

Choices are for Everyone

Continuing the Movement

Toward Community-Based Supports in Connecticut

A Plan in Progress

Guided by the Principles of the Americans with Disabilities Act
and the Olmstead Decision

A collaboration among:

The Connecticut Department of Social Services
The Connecticut Community Options Task Force
The Connecticut Long-Term Care Planning Committee

March 2002

Patricia A. Wilson-Coker, Commissioner
Department of Social Services

TABLE OF CONTENTS

PREFACE	1
I. INTRODUCTION	4
<i>STORY Emotionally Homeless</i>	7
II. EXISTING PROGRAMS (For Community-Based Services and Screening to Divert Individuals from Institutions)	8
<i>STORY Dreaming of Independence</i>	13
III. RECENT INITIATIVES	14
<i>STORY Tom's New Life</i>	20
IV. TARGETS (For Deinstitutionalization and Diversion from Institutions)	21
<i>STORY A Long Odyssey Home</i>	25
V. BARRIERS to COMMUNITY INTEGRATION	26
<i>STORY From a Nursing Home to My Own Home</i>	29
VI. ACTION STEPS	30
<i>STORY 31 Years Old and in a Nursing Home</i>	34
VII. CONCLUSION	35
APPENDICES	

APPENDICES

“Choices are for Everyone” Background Information and Community Input

- A. The Community Options Task Force
- B. The Planning Process for “Choices are for Everyone”
- C. Report on Public Hearings held Throughout Connecticut
October 26 – November 1, 2000
- D. Comments and Questions Raised at Public Hearings and Forum held
October 26 – December 12, 2000
- E. Barriers to Community Integration
Identified by Persons with Disabilities and Other Stakeholders
- F. Community-Based Support Priorities
Identified by Persons with Disabilities and Other Stakeholders

Connecticut Planning

- G. Connecticut’s Planning for Community Alternatives

Connecticut State Services

- H. Additional Services Provided by State Agencies
- I. Recent Deinstitutionalization Efforts in Connecticut
- J. Screening and Assessment Tools to Divert People from Institutions

PREFACE

On July 26, 1990, the President signed the Americans with Disabilities Act (ADA).¹ This civil rights legislation was designed to give people access to a broader range of opportunities by making it illegal to discriminate in areas of employment (Title I), public services furnished by governmental entities (Title II), and public accommodations (Title III). The stated purpose of the ADA was “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”

On June 22, 1999, The United States Supreme Court decided the *Olmstead v. L.C.* case, holding that “unjustified isolation,” caused by unjustified placement or retention of persons with disabilities in institutions, “is properly regarded as discrimination based on disability,” in violation of the ADA.² In the decision, the Court established specific conditions when placement of persons with mental disabilities in community settings rather than in institutions is required:

The State’s treatment professionals have determined that community placement is appropriate;

The transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and

The placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.³

Federal regulation requires public entities to make “reasonable modifications” to their policies, practices, or procedures in order to avoid discrimination on the basis of disability, unless the modifications would “fundamentally alter” the nature of the service or program.⁴ In *Olmstead*, the Court held that the State’s fundamental alteration defense included consideration of “the cost of providing community-based care to the litigants, . . . the range of services the State provides to others

¹ 42 U.S.C. 12101 *et seq.*

² 527 U.S. 581, 597 (1999).

³ *Id.* at 587. Although the *Olmstead* case involved two women with mental retardation and psychiatric disabilities, the decision has been interpreted to apply to a broader population.

⁴ 28 CFR §35.130(b)(7).

with mental disabilities, and the State's obligation to mete out those services equitably.”⁵

In addition, four Justices stated that the reasonable modification standard would be met if the State had:

A comprehensive, effectively working plan of placing qualified persons with disabilities in less restrictive settings; and

A waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.⁶

On March 22, 2000, the Connecticut Community Options Task Force met for the first time. This group had been established by the Long-Term Care Planning Committee and the Department of Social Services to actively participate in the development of a Community Options Plan for Connecticut. The men and women of this advisory group, made up of adults of all ages with various disabilities, family members of persons with disabilities, and representatives from the elder community, worked hard on Connecticut's Community Options Plan, entitled “Choices are for Everyone,” for two years. From the beginning, their vision for Long-Term Community Options Planning was:

VISION STATEMENT

To assure that Connecticut residents with long-term support needs have access to community options that maximize autonomy, freedom of choice, and dignity.

Development of the “Choices are for Everyone” document has been governed by the following Principles:

1. *Hope:* Connecticut residents with long-term care needs must be assured that a *home* and a *life* in the community can and will be available to them within a reasonable time.

⁵ 527 U.S. at 597.

⁶ *Id.* at 605-606.

2. *A Home:* Fundamental to community living is a *home*. The home must be accessible, safe, and affordable.

3. *A Life:* Individuals living in the community must have a *life* as well as a home. Priorities for a life include employment and recreation opportunities, individual supports, transportation, quality assurance, and a welcoming community.

4. *Transition:* Individuals now living in institutions as well as in family homes must be identified and provided with information about independent living. For those who desire it, individuals must be assisted to make *transition* to the least restrictive environment.

5. *Adequate Funds:* Individuals must have *adequate funds* under their control so that they can transition to and remain in a home and have a full life in their community.

This “Choices are for Everyone” document is Connecticut’s comprehensive plan for community integration. Connecticut is committed to increasing community options to enable individuals to live in more integrated settings. In this document, “persons with disabilities” refers to all people covered by the ADA. The ADA covers persons of all ages (from newborn babies through elders) and includes any disability which “substantially limits one or more of the major life activities”⁷

The “Choices are for Everyone” document is a “plan in progress” and should be reviewed periodically to monitor its effectiveness. And it should remain “in progress” until choice from a wide range of options becomes fully realized as the norm in Connecticut.

⁷ “The term ‘disability’ means, with respect to an individual (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.” 42 U.S.C. 12102.

“The phrase physical or mental impairment includes but is not limited to . . . orthopedic, visual, speech and hearing impairments, cerebral palsy, epilepsy, muscular dystrophy, multiple sclerosis, cancer, heart disease, diabetes, mental retardation, emotional illness, specific learning disabilities, HIV disease (whether symptomatic or asymptomatic), tuberculosis, drug addiction, and alcoholism. . . . The phrase major life activities means functions such as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working.” (28 CFR 35.104.)

I. INTRODUCTION

Choices are for everyone, or they should be. For people with disabilities, the choice of where to live has often been limited, not by the lack of personal ability, but by the absence of accessible environments and supports necessary to live successfully in the community and by the lack of information about available options. This is true whether the disabilities arise from physical or mental impairment.

One major reason that options are restricted is that few homes or apartments are designed to accommodate persons with disabilities. In this area, we need to take a lesson from history. Until modern times, the doorways of private homes were designed to be only five feet high, since it was relatively rare to know someone who was tall. As a society, we now make our doorways higher because it is expected that taller people will need to use them. Yet the “standard” doors in modern homes remain only 30 inches wide, on the assumption that no one who uses a wheelchair will need to enter. We rarely build ramps or slow inclines to our doors, even though these simple accommodations would ease access for everyone - people pushing strollers, as well as people who use mobility devices. Like the colonial homes with their low doorways, support services for persons with disabilities also tend to be designed with old norms in mind.

Just as narrow doorways are obstacles for people with limited mobility, doors are often closed to people with other types of disabilities by the lack of appropriate supports, or by bureaucracy and stigma. Stigma about certain conditions (especially mental illness, mental retardation and AIDS) can pose obstacles that are more challenging than the architectural ones. People with psychiatric disabilities may find their way blocked by the fears and ignorance of society, including potential neighbors and employers. People with the label of mental retardation may have to wait outside the door for years until their names come to the top of the waiting list. People with multiple issues are often referred from the door of one system to the door of another and another, creating confusion, frustration, and distrust. Some people in these categories may even end up homeless.

Public attitudes can create barriers, or they can open doors to inclusion. At times it has been assumed that people with disabilities need someone else to direct their lives and monitor their services. Too often it has been taken for granted that “those people” must reside in institutional settings in order to receive the care and protection they need; and institutional settings are sometimes designed to serve the

convenience and efficiency of caretakers rather than the comfort and preferences of their residents. The institutions are a form of segregation, keeping people with and without disabilities from experiencing relationships that could build understanding, collaboration, friendship, and trust and that would promote ongoing health.

At long last, however, the biases that favored institutionalization are beginning to change.⁸ Such change is needed because society is changing. Principles of universal design are increasingly recognized as a way to address the needs of persons with disabilities, not by special accommodations, but by designing environments and supports that work for everyone. As the Baby Boom Generation ages and as technology enables us to survive illnesses and traumatic events and to adapt our environments to our needs (rather than forcing us to adapt to our environment), more people with disabilities will be setting goals and pursuing them. And they - we - will want more choices.

Choices require options from which to choose. Informed choices require knowledge about the options that are available or could be made available.

Developing a range of choices means recognizing that there are diverse points of view about how people with disabilities should be supported in meeting their needs, and that no one solution will work for everyone. Although persons with physical, psychiatric, and cognitive disabilities may all have support needs, the design and effective delivery of those supports will vary for age and type of disability, as well as individual need. For persons with multiple disabilities, the needs and necessary supports are even more complex. In addition, children and families may have different needs.

Recognizing that every person is unique, and that even people with the same “diagnosis” do not necessarily need the same things, systems of community support should offer a menu of options that can be combined in different ways. Starting with the person’s individual goals and needs is essential. A number of person-centered planning tools are available to help with this process. People may need housing, transportation, hands-on care, or simply verbal reminders to carry out certain tasks such as eating or taking medication. Some may need the services of a personal manager to coordinate appointments, transportation, payment of bills,

⁸ When President George H. W. Bush signed the Americans with Disabilities Act in July 1990, he stated, "with today's signing of the landmark ADA, every man woman and child with a disability can now pass through once-closed doors into a bright new era of equality, independence and freedom."

and so on. The key is to look at what people actually need instead of trying to fit them into slots.

Having an array of services and supports available is of no value if the people who need those services and supports do not know about them or how to access them. Thus, people with disabilities of all ages need to know about the environments and supports now available that could enable them to create and manage a successful life in the community. Families of people with disabilities need to know the availability of supports and services so that they can keep their family member at home or endorse their decision to live independently in the community. Providers of care need to know the possibilities too, so that they can recommend, ease, and/or assist living in the community. And people without disabilities need to know about the potential for individuals with all types of disabilities to live fulfilling lives in the community so long as adequate and appropriate supports are available. Hopefully with this knowledge will come acceptance of the individuals themselves in the community and ultimately an end to the discrimination that many people with disabilities endure.

As we have said, there are no real choices without alternatives and information available to the decision-maker. Therefore, the focus of this plan is on identifying ways to expand the available options for all persons with disabilities (including supports to their families) and to enhance the information available to them so they can make informed choices about how best to get their needs met.

Emotionally Homeless

I think many people take their privacy for granted. My privacy is something I think about all the time.

I am 43 years old, and have been living in a nursing home for almost four years. I am not here because I am incapacitated, elderly, or have dementia. I am here because there is a lack of affordable housing for people under the age of 62 with low incomes such as disability benefits.

In the spring of 1997 I was living at the YMCA, disabled, but receiving no assistance because my case had fallen through the cracks of Connecticut's social service system. (Two-and-a-half years later, after going through a court hearing, I was found to be eligible for Social Security Disability.) I was admitted to the nursing home for rehabilitation following surgery. But when I was better, I had nowhere to go so I stayed in the nursing home.

Living in the nursing facility, I am subjected to constant noise, light, and confused people, as well as other aspects that are part of being institutionalized. I feel that my identity has been hidden in a twisted maze of medical records, daily reports on my bodily functions, and state regulations. Staff come in and out of my room performing their jobs. I often feel that I live in someone's workplace. My privacy has become public.

Another difficult aspect of living here is death. I become very close to my fellow residents. I grow to love them, yet I know that I am in the prime of my life and they are nearing the end of theirs. Although I consider it an honor to share this time in their lives, their loss is devastating to me. I have shed tears at many a funeral because they have become like family to me.

People often tell me I should count my blessings that I have a roof over my head and three square meals a day. After almost four years of struggling to survive each day with some dignity, that just doesn't cut it anymore. I feel emotionally homeless.

What I experience living in a nursing home is not a result of abuse or neglect. On the contrary, I have received a great deal of nurturing from the staff, volunteers, and fellow residents. My experience is negative because I live in a place where I don't belong.

I long for the day when I can enjoy my own apartment. There is no peace or tranquillity living in an institution. That is something that can only be achieved in the privacy of one's own home.

II. EXISTING PROGRAMS

(For Community-Based Services and Screening
to Divert Individuals from Institutions)

Connecticut provides several long-term care programs designed to assist individuals of all ages and disabilities to live in the community. Along with the programs administered directly by State agencies is a myriad of local community supports and services throughout Connecticut's towns that are administered by local government agencies, non-profit and for-profit organizations, as well as volunteer groups.

Major State Agency Programs

1. Department of Social Services (DSS): DSS provides a broad range of services to people who are elderly or have disabilities, families, and individuals who need assistance in maintaining or achieving their full potential for self-direction, self-reliance, and independent living. It administers over 90 programs. By statute, it is the State agency responsible for administering a number of programs under federal legislation, including the Social Security Act (Medicaid comes under Title XIX of the Social Security Act), the Rehabilitation Act, the Food Stamp Act, and the Older Americans Act. DSS administers the Connecticut Home Care Program for Elders, a portion of which is State-funded, and other State-funded programs such as the Connecticut AIDS Drug Assistance Program and the Connecticut Pharmaceutical Assistance Contract to the Elderly and the Disabled Program.

2. Department of Mental Retardation (DMR): DMR provides case management, residential services and supports ranging from individualized supports to group homes as well as regional centers and the Southbury Training School; day supports ranging from day activity programs to prevocational and supported employment services; DMR also provides respite care, and family support to persons with mental retardation. In addition, DMR is the lead agency for the Birth to Three System in Connecticut. This system serves infants and toddlers with developmental delays. Altogether, DMR assists over 18,000 individuals and their families.

3. *Department of Mental Health and Addiction Services (DMHAS):* DMHAS has 18 Local Mental Health Authorities statewide that provide a vast array of community mental health services for persons with mental illness. In addition, DMHAS operates inpatient hospitals and facilities for persons with severe addiction and/or psychiatric problems. In FY 2001, DMHAS provided mental health services to 30,491 persons in the community and 2,455 persons in inpatient facilities.

4. *Department of Children and Families (DCF):* DCF provides a variety of community-based and institutional services for children and adolescents with disabilities and their parents. A prerequisite to these services is the requirement that individuals be involved with the Department in some way, either through protective services, juvenile justice or voluntary services programs. DCF, in collaboration with DSS, is currently developing a significant initiative to reorganize behavioral health services for children in the community, called Connecticut Community KidCare.

5. *Department of Economic and Community Development (DECD):* DECD oversees all State statutes related to accessible housing. In addition to being a key partner in the State's assisted living demonstrations, it administers capital grants for the conversion of adaptable living units to accessible units for persons with disabilities. The agency is also developing a statewide registry of accessible housing, which is administered by Co-op Initiatives, Inc.

6. *Office of Protection and Advocacy for Persons with Disabilities (P&A):* P&A is an independent State agency created to safeguard and advance the civil and human rights of people with disabilities. By providing various types and levels of advocacy assistance, P&A seeks to insure that people with disabilities and their families are better informed, equipped, and supported to advocate for themselves and others. Each year P&A provides information and referrals to over 7,000 people, monitors over 1,200 abuse and neglect investigations, and provides advocacy representation to over 900 individuals and families.

Some Specific Community-Based Services

1. Medicaid Waivers: The Medicaid waiver programs offer home and community-based services to individuals in specific target populations who would otherwise need to receive services in institutional settings. DSS currently administers four of the five home and community-based services waivers under Medicaid and DMR administers the fifth waiver. Many of the waivers have very active consumer and family involvement in the design and operation of the program.

a. Elder Waiver: The Elder Waiver, a part of the Connecticut Home Care Program for Elders (CHCPE),⁹ offers a wide range of home and community-based services to approximately 8,300 elders, age 65 and older, each month who would otherwise be in a skilled nursing facility. These services include adult day health, homemaker, companion, chore person, home delivered meals, emergency response systems, case management, assisted living, minor home modifications, and home health services.

An important aspect of the CHCPE is its pre-screening process. The program requires that nursing homes assure that persons 65 years of age and older who are within the home care program's income guidelines receive the CHCPE brochure and application form prior to admission. Individuals are screened by the CHCPE staff to confirm that they need the level of care provided by the nursing home and that they have been given information about home care as an alternative. This process has reduced the likelihood that elders choosing nursing homes do so without information about available options in the community.

In July 2000, the Centers for Medicare & Medicaid Services (CMS) approved a five-year extension of this waiver. An eligibility expansion was passed by Connecticut's General Assembly in 2000 that allows individuals who have incomes over 300 percent of Supplemental Security Income (SSI) to qualify for the CHCPE. This new financial eligibility standard has been implemented in

⁹ CHCPE has two components. One component is the Elder Waiver, a Medicaid waiver, which is funded jointly by State and Federal dollars. The functional need standard required for the Elder Waiver is the individual's need for long-term nursing home care. The other component is the state-funded CHCPE. The functional need standard for this component is the individual's need for short or long-term nursing home care or whether the individual is at risk of hospitalization or short-term nursing home placement.

the State-funded portion of CHCPE. However, CMS has yet to allow the new eligibility standard to be implemented for the Elder Waiver.

b. *Personal Care Assistance (PCA) Waiver:* At this time, Connecticut does not cover personal assistance services as a Medicaid State Plan service, but rather as a waiver service. The waiver, which began in 1997, provides personal care assistance services to persons with physical disabilities who are between the ages of 18 and 64. It is a consumer-directed service model and as of February 2002 has 307 persons enrolled. The program can accommodate 409 people.

c. *Acquired Brain Injury (ABI) Waiver:* This waiver provides 21 specific behavioral and support services to persons between the ages of 18 and 64 with acquired brain injury. As of February 2002, 123 people are enrolled in the program and many other individuals are in the process of applying. The program can accommodate 253 people in Year 3 of the waiver.

d. *The Katie Beckett Model Waiver:* This waiver offers full Medicaid eligibility, case management, and home health services primarily to children with disabilities who would normally only qualify for Medicaid in an institution under the institutional "deeming" rules. The program currently serves 125 people, which is the maximum funded under State law.

e. *Department of Mental Retardation (DMR) Waiver:* This waiver offers a variety of services, including case management, residential habilitation, day habilitation, prevocational services, supported employment services, respite, family training, and environmental modifications to approximately 5,500 persons with mental retardation who would otherwise be institutionalized. More than 400 of the clients served are children.

2. *State-Funded Home Care Program:* A portion of the CHCPE is supported solely by State funds and provides the same services as the Medicaid Elder Waiver. The program serves over 3,200 elders age 65 and older who are at risk of institutionalization and have assets greater than the Medicaid limit. In 2000, Connecticut's legislature passed an expansion of the State-funded portion of the CHCPE to allow individuals with incomes over 300 percent of SSI to qualify for the program. As mentioned previously, Connecticut is awaiting approval to implement this income expansion for the Medicaid waiver portion of the CHCPE. However, the expansion for the State-funded portion of the CHCPE was fully implemented in October 2000.

3. *Pre-Admission Screening (PAS) Review:* Besides the screening process that is part of CHCPE, the PAS screening process requires that prior to admission to a nursing home, all persons diagnosed with mental retardation or mental illness be reviewed by the appropriate mental retardation or mental health agency in the state to determine whether nursing home placement is necessary and appropriate. The screening process helps to assure that these individuals receive information about community alternatives before accepting institutional placement.

4. *Medicaid for the Employed Disabled:* Connecticut is implementing the Federal "Ticket to Work/Work Incentives Improvement Act" that enables persons with disabilities who are under age 65 to earn up to \$75,000 and still qualify for Medicaid benefits. The program allows persons with a disability to engage in employment without jeopardizing needed medical services provided through the Medicaid program. It also allows certain individuals to retain other necessary services enabling those individuals to remain actively employed. The Personal Care Assistance Waiver program is also available to these individuals if they meet program requirements.

5. *Community-Based Services:* This State-funded program is designed to augment services that people may be receiving from Medicaid's home health benefits. The program serves approximately 1,600 individuals each month and provides homemakers, companions, personal emergency response systems, and adult companions. Privately employed companions may perform personal assistance. Almost 400 (or 25 percent) of the people using this program have self-directed services.

Local Community Supports and Services

Connecticut has many local community organizations, such as the five Centers for Independent Living, that work with individuals with disabilities to access the services they need, and numerous Advisory Councils for Persons with Disabilities and Mental Health Councils that provide input to various organizations and agencies. Connecticut also has several non-profit organizations focused on new housing initiatives for persons with disabilities. Consumer focused training programs, such as those for persons with psychiatric disabilities and peer run programs, such as warmlines and drop-in centers, are also important components of the system.

Dreaming of Independence

My first real taste of independence occurred when I began to attend college. I moved onto campus, and began hiring students to be my personal assistants. I never had to worry if an assistant called out sick, as there was a whole network of students I could call upon to support me.

After graduation (and many good late night parties), I moved back home. My biggest fear was, and still is, what will I do when my mother can no longer support me? In some ways it makes me sad that I need to look at my mother for support rather than simply having a mother-daughter relationship.

Twelve years ago my mother and I began exploring housing options. My mom and I were having the same dream about me not having to live with my aging parents. If anything happened to them, I would have no other choice but moving into a nursing home. Then a friend asked me to be a part of her Circle of Friends as she was beginning to dream about developing a housing cooperative. By attending my friend's circle meeting, I learned of a model of a housing cooperative, where home owners with and without disabilities could share their gifts and talents while supporting one another.

I was able to begin my Circle of Friends after three wonderful individuals listened and drew out my vision. At the first circle meeting, I shared my dream, which was also to create a housing cooperative. A circle member turned my dream into reality by developing the first inclusive housing cooperative in my community.

Just over a year ago, on December 1, 2000, I celebrated my Tenth Anniversary of living independently in the four-unit cooperative. The cooperative has not developed exactly the way I dreamed: my co-op neighbors do not see me as an active career woman striving to be independent with the support of personal assistants. Not having enough funds for support, I have developed a network of friends who assist me with dinner. Family and close friends are critically important when my assistant cannot come to work, or when I am in the middle of hiring someone.

I am hoping that the Olmstead activities in Connecticut will free people of all ages from nursing homes and provide the needed support in the community to prevent institutionalization. Just as important, though, is supporting people who are struggling to be successful in their communities. I cannot pursue all of my dreams, as the constant need to manage personal assistance issues is overwhelming. My gray hair can attest to this!!

III. RECENT INITIATIVES

In addition to the existing services that are presently being provided, the State is moving in the direction of creating additional home and community-based services.

1. *The Long-Term Care (LTC) Planning Committee:* The LTC Planning Committee was established in 1998 to create a forum for State agencies to better coordinate their long-term care planning efforts. The Committee is composed of the co-chairs and ranking members of the General Assembly's Aging, Human Services, and Public Health Committees and representatives from ten State agencies. The Committee is charged with developing a long-term care plan every three years. The Long-Term Care Plan must cover home and community-based care, supportive housing, and nursing facility care. The Committee issued a Preliminary Plan in 1999 and a full Long-Term Care Plan in 2001. The Committee was initially charged to develop a Long-Term Care Plan for elderly persons and so these first two Plans were focused on the elderly. In 2001, the General Assembly broadened the Committee's mandate and required that all future Long-Term Care Plans be applicable to all individuals with disabilities, regardless of age. In addition, at the request of the General Assembly, the Committee issued a report on the Connecticut Home Care Program for Elders that recommended an expansion of the program's income methodology. In 2000, the General Assembly, at Governor Rowland's request, adopted the Committee's Home Care Program proposal. The Committee has also provided the structure for State agencies to work more cooperatively amongst themselves and with consumers and advocates and provided an opportunity for the State to take advantage of grant opportunities, such as the Nursing Facility Transition grant, described below.

2. *The Nursing Facility Transition (NFT) Grant:* Connecticut has received from the federal government a Nursing Facility Transition to Independent Living Grant for \$800,000 over three years. The Connecticut Association of Centers for Independent Living (CACIL) will be responsible for the overall management and administration of the grant activities including implementation of the project's objectives.

The goal of the three-year grant project is to develop and implement policies and procedures that will allow individuals to live in the community and to successfully transition 150 people back to the community. The project will develop a variety of products to better inform State agency staff, professionals in the community, and

nursing facility residents about the concepts of independent living and self-direction. A self-assessment tool and a "step-by-step" guide to community transition will be developed, so that nursing facility residents and their families can gauge their readiness for a successful transition. In addition, a Common Sense Fund will be established to help pay for items that are usually not covered by government programs, such as rental deposits, utility deposits, and household goods.

3. *The Connect to Work Project:* The Department of Social Services' (DSS) Bureau of Rehabilitation Services (BRS) has been awarded two federal grants to support the employment of persons with disabilities in the competitive labor force. As a result, BRS has established the Connect to Work Center.

The primary goals of the Connect to Work Project are to:

- a. Establish a statewide network of benefits counselors, available to individuals with disabilities, families, employers, service providers and advocacy groups;
- b. Provide a single access point for information and assistance around benefits and services, connecting the key components of employment, health care, personal assistance and benefits counseling;
- c. Provide training, public education and outreach around benefits and services offered within Connecticut (with a particular emphasis on the Medicaid for the Employed Disabled Program); and
- d. Conduct policy review and policy development to enhance opportunities for individuals with disabilities to enter the labor force.

4. *Assisted Living Initiatives:* The following initiatives will enable qualified individuals to age in place, thereby avoiding unnecessary or early transfer to a nursing facility.

a. *Congregate Housing:* Through a collaborative effort of the Department of Economic and Community Development (DECD), Department of Public Health (DPH), the Office of Policy and Management (OPM) and DSS, Connecticut is making assisted living services available in State-funded congregate housing facilities for individuals who are at least 62 years old. Seventeen of the State's 24 congregates have elected to add assisted living services to their facilities through a combination of DECD and DSS funding. This initiative began in

October 2000, and when fully implemented will provide assisted living services to over 300 individuals. As of December 31, 2001, 121 congregate residents have received services through the program.

b. United States Department of Housing and Urban Development (HUD)

Housing: A similar assisted living program is being piloted in two federally funded Housing and Urban Development (HUD) complexes. This pilot also began in October 2000 and will ultimately provide assisted living services to over 60 people in the two HUD facilities. As of December 31, 2001, 56 residents in the two HUD facilities were receiving services through the pilot.

c. Assisted Living Demonstration Project: Connecticut is developing five assisted living pilot projects for elders, which will provide affordable assisted living services using a unique combination of Medicaid and State funding. DECD will provide annual funding for rental subsidies and \$12 million in grant funds to the Connecticut Housing Finance Authority (CHFA), in combination with \$3 million in existing CHFA funds, for development. Up to 300 new units of housing will be created, with the first developments becoming operational in 2003.

5. Personal Care Assistance (PCA) Pilot: Connecticut is implementing a State-funded 50-person Personal Care Assistance Pilot to make self-directed personal care services available to persons transitioning from the Medicaid Personal Care Assistance waiver to the State-funded portion of the Connecticut Home Care Program for Elders (CHCPE), as well as for others on the CHCPE program who do not have access to formal services in their community. This program allows a seamless transition for waiver clients when they turn 65 and become eligible for the CHCPE. As of January 2002, the pilot program had 29 persons enrolled.

6. Long-Term Care Pre-Admission Screening: Similar to the screening required for persons qualifying for the CHCPE, this new program requires that hospitals and nursing homes screen all long-term care applicants, regardless of income. DSS will receive all screening documentation prior to admission and will provide educational materials for distribution to all applicants. With this initiative all individuals who need long-term care will have the opportunity to learn about options available to remain in the community.

7. *Moratorium on Construction of Nursing Facility Beds:* In 1991, Connecticut established a moratorium on the construction of new nursing facility beds with limited exceptions. New nursing facilities approved prior to the moratorium were permitted to proceed to construction and licensure. Therefore, the number of licensed beds continued to increase through 1994. Since then the number of beds has stabilized and has actually declined by over 800 beds over the past two years. Since 1997, there has also been a reduction in the average number of nursing facility Medicaid clients by more than 1,200 and there continues to be a significant number of facilities failing to meet the minimum occupancy target of 95 percent. Given this weakness in demand for nursing facility beds and the desire to increase the use of less institutional alternatives, the General Assembly recently extended the moratorium to 2007.

8. *Connecticut Behavioral Health Partnership:* DSS, the Department of Children and Families (DCF), and the Department of Mental Health and Addiction Services (DMHAS) have formed the Connecticut Behavioral Health Partnership to plan and implement an integrated public behavioral health service system for adults, children, and families. The two initiatives under this Partnership are the Connecticut Community KidCare led by DCF and DSS and the Recovery Healthcare Plan for Adults led by DMHAS and DSS. The Partnership has three goals: administrative integration, service delivery redesign, and revenue maximization. Administrative integration will enable the State to integrate funding streams in order to support comprehensive and longitudinal care planning and reduce unnecessary institutional care. The service delivery design reforms are focusing on improved community-based, wraparound service planning for children and adults in order to avoid unnecessary hospital admissions and extended institutional stays, and to improve client satisfaction and outcomes with respect to independent functioning and quality of life. Finally, the Departments are seeking to improve federal financial participation by implementing child and adult rehabilitation options to cover a broader range of community-based services.

9. *Task Force on Personal Assistance:* A task force has been established with the objective of transforming the position of a personal assistant into a “real job.” The task force is studying the barriers that now cause personal assistance to be viewed as a part-time, low-skilled occupation, instead of the important support service it is. Some of the more pressing issues include the lack of health insurance and worker’s compensation. The task force is spearheaded by the Connect to Work Center of BRS. The Center is funded by federal grants from the Centers for Medicare and Medicaid Services and the Social Security Administration. Members of the group

include representatives from various State agencies, personal assistants, and people who employ personal assistants.

10. Increased Housing Options for People with Psychiatric Disabilities (the PILOTS program): PILOTS is a public/private collaborative effort to provide community-based options for affordable housing and support services to persons with serious mental illness and/or chemical dependency who are homeless or at risk of homelessness. Effective July 1, 2000, the first phase of PILOTS was funded to create close to 200 housing units serving over 240 families and individuals by State Fiscal Year 2001. Supportive housing is a proven, effective means of re-integrating families and individuals with chronic health challenges into the community by addressing their basic needs for housing and on-going support.

11. Interagency Collaboration between DMHAS and DCF regarding Families at Risk and Transitioning Youth:

a. Project SAFE: Project SAFE responds to the needs of child welfare clients who have substance abuse problems. The Project provides priority access to evaluations, drug screens and outpatient treatment services. The goal is to promote child and family safety by enhancing services that address specific social, relational and emotional needs among this population.

b. Young Adult Services: This program is designed to provide ongoing services to youngsters aging out of DCF. These young people have histories of extensive residential placement, psychiatric hospitalization, and multiple complicated social, psychological and familial difficulties.

12. Funding to Continue Enhancing the Development of Community Services: As of July 1, 2000, the legislature appropriated additional money to expand the jail diversion program. The program is designed to screen and assess individuals diagnosed with mental illness and substance abuse disorders who repeatedly cycle through the criminal justice system in part due to these disorders. The goal is to deflect inappropriate institutionalization and instead provide individuals a range of mental health, substance abuse and other support services in the community.

13. *Pilot Peer Engagement Specialist Initiative:* Under Public Act No. 00-216, DMHAS is required to establish a “pilot peer engagement specialist program.” The focus of this program is to hire, train, and deploy individuals who are in recovery from psychiatric disabilities to provide intensive community support and case management services for people who otherwise would meet criteria for mandated (or assisted) outpatient treatment. The intent of the Act is to evaluate an alternative approach to increasing adherence to outpatient treatment among this high-risk population to reduce arrests, emergency room visits, and hospitalizations.

14. *DMHAS Recovery House Initiative:* In FY 2001, transitional housing and case management services were provided to clients with substance abuse disorder or co-occurring behavioral health disorders. One 20-bed facility opened in Hartford in July 2000 and another 20-bed program opened in New Haven during the fall of 2000.

15. *Center for Mental Health Services Grant for Community Integration:* DMHAS was recently awarded a three-year \$60,000 grant from the federal Center for Mental Health Services to encourage inclusion of people with psychiatric disabilities in the community integration plan. The Hartford area has been selected to pilot a project that will focus on identifying barriers that exist to community services, the roles of consumers/families/advocates in the planning process, and issues unique to people with mental illness.

16. *Care/Case Management Demonstration Projects:* In FY 2001, demonstration projects to support care/case management programs for clients with substance use and co-occurring disorders began.

17. *No New Admissions to Southbury Training School (STS):* No new admissions have been accepted to STS since July 1986 when the census was over 1,100. In 1997, a statutory prohibition to accepting new admissions at STS was enacted. The census in December 2001 was 631.

Tom's New Life

For many years, Tom lived in one of the regional centers run by the Connecticut Department of Mental Retardation. He had labels of autism and mental retardation. Tom had a reputation for severe behavior problems and he took a variety of medications, including sedatives.

At the regional center, Tom did not have much control over his life, his schedule, or his surroundings. A man who thrives on privacy, Tom had to share his bedroom with someone else. His personal belongings, including his rocks, shells, and airplanes, were in the common area of a unit that he shared with five other people. Everyone who lived or worked on the unit had access to Tom's possessions. He was very protective of these possessions. This often caused him to act out.

Tom had a reputation for banging his head on hard objects. Many times he had used his head to break glass and he had caused himself some serious injuries. As a result, Tom wore a helmet when he attended his day program, a program that paid him little, if any, wages. He also wore this helmet while riding in the van.

Tom did not get out into the community often and, if he did, it was always in a group. He did not have the opportunity to do many of the things most of us take for granted like going shopping, going for train rides, or going to work. He did not have the opportunity to try new things when he felt like it.

But those days are over now. Today Tom lives in a group home with two other men close to his own age. He has his own room, decorated the way he likes, with textured wall treatments that he loves and finds soothing. He keeps most of his important personal possessions in his room, where he has control over who comes in and out. Tom has a fish tank in the living room, where he enjoys it along with his housemates. He likes being able to share this prized possession with others.

Tom has a small business doing lawn maintenance, recycling, and computer work. He has many regular customers. A staff person works along side to provide the necessary support. Tom is always out in the community, going shopping and to parties. He has been to New York City on the train. Tom's support people know him well and are highly respectful of his choices and this makes a huge difference.

The helmet is no longer part of Tom's life. He takes much less medication than he did when he lived at the regional center. He is less anxious, more social, and happier. Tom's family is happy to see his satisfaction with his new life. Tom is only one of many people with disabilities who, with appropriate support, is living successfully in the communities of Connecticut.

IV. TARGETS for DEINSTITUTIONALIZATION and DIVERSION from INSTITUTIONS

Connecticut's home and community-based programs and new initiatives work to transition individuals residing in institutions back into the community and to divert entrance, or re-admission, into institutions.

Based on the current biennium budget (July 1, 2001 – June 30, 2003), the various agencies that administer Connecticut's home and community-based programs -- the Departments of Mental Health and Addiction Services (DMHAS), Mental Retardation (DMR), Social Services (DSS), and Children and Families (DCF) -- have estimated the number of individuals their programs can help transition back to the community and the number who can be diverted from entering an institution in the first place or prevent their re-admission into an institution. The attached charts reflect the agency estimates for each year of the biennium.

***TARGETS for DEINSTITUTIONALIZATION
FOR INDIVIDUALS NEWLY ENROLLED
DURING THE CURRENT BIENNIUM
(2001 – 2003)***

STATE AGENCY	SFY 2001-02	SFY 2002-03
DMHAS	35	35
DMR	40	40
DSS	341	376
DCF	87	55
TOTAL	503	506

DMHAS: This number reflects mental health clients who would not normally be discharged because of their high level of need for specialized services and resources. However, in both state fiscal years (SFY 2002 and 2003), approximately 2,000 inpatient mental health clients will be discharged routinely.

DSS: For SFY 2001-2002, this number reflects individuals who resided in long-term care facilities during the State fiscal year, who are or will be able to move to a community placement because of the Connecticut Home Care Program for Elders Program (CHCPE), the Katie Beckett Model Waiver, the Acquired Brain Injury (ABI) Waiver, or the Personal Care Assistance (PCA) Waiver. For SFY 2002-2003, this number reflects the number of individuals that DSS expects to be able to deinstitutionalize due to these same DSS programs.

DCF: The number of residential placements will be reduced to 1,355 in SFY 2002 and 1,300 in SFY 2003.

***TARGETS for
DIVERSION FROM INSTITUTIONS
FOR INDIVIDUALS NEWLY ENROLLED
DURING THE CURRENT BIENNIUM
(2001 – 2003)***

STATE AGENCY	SFY 2001-02	SFY 2002-03
DMHAS	1,600	1,600
DMR	60	50
DSS	956	1,056
DCF	100	150
TOTAL	2,716	2,856

DMHAS: This number reflects individuals with mental illness who would be newly enrolled in the DMHAS system and who would require the most intensive community services available. If these supports were not available, these clients most likely would be hospitalized.

DSS: These numbers reflect the number of newly enrolled individuals receiving services in the community, who, but for the CHCPE, the Katie Beckett Model Waiver, the ABI Waiver, or the PCA Waiver, would be living in long-term care facilities.

**INDIVIDUALS BEING SUPPORTED IN THE COMMUNITY
DURING THE CURRENT BIENNIUM
(2001 - 2003)
(DOES NOT INCLUDE NEWLY ENROLLED CLIENTS)**

STATE AGENCY	SFY 2001-02	SFY 2002-03
DMHAS	1,130	1,130
DMR	6,920	7,020
DSS	11,000	11,796
DCF	8,419	10,000
TOTAL	27,469	29,946

DMHAS: This number reflects mental health clients receiving the most intensive community services available. If these supports were removed, these clients would most likely return to the hospital. At the same time, approximately 30,000 mental health clients will be served in the community in SFY 2002 and 2003.

DMR: These numbers reflect individuals who receive residential supports. It does not include individuals who receive day supports (almost 9,000 individuals, many of whom also receive residential supports). In addition, DMR provides a comprehensive array of family supports including respite, family support grants, temporary supports, recreation, and crisis intervention services to over 3,500 individuals who do not receive residential supports.

DSS: These numbers reflect the number of individuals receiving services in the community, who, but for the CHCPE, the Katie Beckett Model Waiver, the ABI Waiver, or the PCA Waiver, would be living in long-term care facilities.

DCF: This represents the number of children and youth who are involved with DCF and who have used one or more behavioral health service in a 12-month period. It does NOT include those children and youth who may have benefited from community programs funded by DCF but who are not committed. This figure is closer to 22,300.

A Long Odyssey Home

Doris, a vital and active 73-year-old woman, received a traumatic brain injury and C6 spinal cord injury in an auto accident. Upon stabilization, Doris was discharged to a nursing home for rehabilitation.

Doris' spouse, Frank, submitted an application for Title 19 on behalf of his wife. For Doris to become eligible for Title 19, she had to spend down a retirement fund. She paid to make her home accessible and purchase a lift-equipped van. When Doris' Medicare coverage ended, it almost meant the end of her rehabilitation therapy. Frank asked that therapy continue, since he wanted to take her home.

The doctor doubted that she could go home because of her lack of function. The nursing home, however, prepared her for removal of the tracheostomy tube, taught her to swallow, to feed herself, and to use a power wheelchair. The doctor did not feel she should go home with the power chair because of her leg spasms. Luckily, the therapist convinced him that the spasms did not affect her control of the chair.

The local independent living (IL) center sent a worker to advise Frank about things that would make it easier for Doris to return home. The IL worker and the nursing home social worker arranged for home-based services through various agencies. The worker from the IL center had a positive influence in Doris' discharge process, both in motivating the nursing home, and in assisting Frank in understanding what was involved with living in the community with a disability.

Doris went home using a power wheelchair from the nursing home because an application submitted to Medicaid while she was still in the nursing home would have been denied. In the nursing home her medications were covered. But upon discharge Frank had to pay \$365 out-of-pocket for her medications. Although he applied for reimbursement through their insurance, there was a cash flow problem.

At home, Doris receives therapy, home health aide and companion services, nursing supervision of her case, and Meals on Wheels. Frank trains the home health aides to work with Doris, fills in when the aides are absent, monitors Doris' health, drives her to church and doctor's appointments, and maintains their home. He is glad to have his wife back home but the responsibilities are tremendous.

The process of bringing Doris home was so much more complex than could be described here. But she had the right people involved -- from a committed spouse, to social workers, therapists, and the IL center staff. The bureaucratic hurdles, the perceptions of doctors, and unfamiliarity with independent living could have made the move impossible. These issues need to be addressed so that more people like Doris can make the long odyssey home.

V. BARRIERS TO COMMUNITY INTEGRATION

In order to plan the appropriate supports to enable persons with disabilities to choose non-institutional settings, it is critical to understand the barriers that prevent such access.

Barriers as Identified by Stakeholders

As part of the process of gaining public input, ideas were gathered from persons with disabilities of all ages, including family members, and other stakeholders, about additional barriers which restrict the provision of home and community-based services. Some issues had broad applicability to individuals of all ages and with all types of disabilities who might need long-term supports; other issues are more specific to particular groups. The barriers identified by stakeholders can be summarized into five broad categories:

1. Lack of public education (including medical and non-medical providers) about available options, and lack of public awareness and support for community choices;
2. Lack of affordable and accessible housing;
3. Lack of assistance to persons with disabilities to help overcome fear, lack of experience, stigma, and the lasting effects of institutionalization and/or discrimination;
4. Lack of adequate and accessible supports in the community (including not only support with activities of daily living, but also transportation, employment, and education);
5. Lack of a sufficiently large, competent (including being culturally knowledgeable), adequately compensated workforce to provide the necessary supports and services.

Federal Restrictions

Many of our systems of support reflect biases towards the institutionalization of persons with disabilities. One of the clearest examples is the Medicaid program. The federal rules governing the Medicaid program have significantly contributed to an institutional bias in service delivery. Since most states depend heavily upon Medicaid for providing long-term services and other supports to their populations (because of the receipt of federal matching funds), the barriers within Medicaid have reinforced institutional biases across the country.

Under federal Medicaid law, nursing home services are *mandatory* and must be covered for everyone who needs them. Community-based long-term care services are *optional*, often created through special waivers, which require the states to set program caps and may result in waiting lists. Under federal rules, persons applying for Medicaid home and community-based services must be offered a choice between institutional and community care, but there has never been any federal requirement that persons applying for institutional placement be made aware of and offered choices in the community.

For instance, current financial eligibility rules for Medicaid are more generous for persons living in institutions than for those living in the community. Similar (but not quite as generous) rules can be applied to persons living in non-institutional settings who need long-term care, but only through a convoluted process of defining them as “institutionalized persons.” This creates undesirable outcomes, such as prohibiting married couples from both qualifying for home and community-based services while maintaining resources to live in the community. If both people were to qualify for these services, they would lose the financial benefits that prevent the impoverishment of community spouses of “institutionalized persons.”

Another example can be found in DSS’s Connecticut Home Care Program for Elders (CHCPE). As stated in Section II, Existing Programs, this program has two parts: the Medicaid waiver, which is called the Elder Waiver, and the State-funded CHCPE. Connecticut’s General Assembly passed an expansion of the financial eligibility criteria for the entire CHCPE in 2000. This expansion allowed individuals with over 300 percent of Supplemental Security Income (SSI) to qualify for the CHCPE, as long as they applied some of their income toward their care and their income did not exceed the cost of nursing home care. Prior to this expansion, if individuals were as little as one dollar over the income limit they would be ineligible to receive CHCPE program services. Ironically, most of these

same individuals would be allowed to apply their income to nursing home care and be covered by Medicaid. Thus, this financial eligibility requirement was, in effect, forcing individuals out of home care and into more-expensive nursing home care. With the passage of the Connecticut statute, the State-funded portion of the CHCPE began to accept individuals over 300 percent of SSI. However, the Federal Centers for Medicare and Medicaid Services (CMS, formerly HCFA) will not allow this financial expansion for the Elder Waiver. Thus, for individuals applying for the Elder Waiver today, if they are one dollar over the income limit, even if they meet other program eligibility criteria, they are deemed ineligible.

But Medicaid is not the only culprit. The Federal Medicare program's recent restrictions on payments for home health services have reduced options for people living in the community. Many programs funded by states also have incentives for institutionalization due to low benefit thresholds and waiting lists implemented to keep programs within appropriations. Insufficient federal funding for the development of accessible housing and transportation options throughout the country create additional barriers to community living. And lack of a national citizens' awareness campaign about available long-term care choices is a major, though too often unrecognized, barrier to community integration.

From a Nursing Home to My Own Home

Sam is a sensitive, intelligent man with a wonderfully dry sense of humor. He also has a rare disease that causes brain tumors. For most of his 51 years, he has lived an independent life. He has a degree in social work and spent his career working for social service agencies. Then, in 1996 he had an accident, which caused him to be hospitalized. It was decided that he could not live on his own after this accident. Therefore he became a resident of a nursing home, where his health deteriorated alarmingly.

Several years ago, at the request of Sam's mother, advocates began to meet with Sam to discuss how he could return to the community he loved. The process of moving someone from an institution to the community is always complicated.

Sam was fortunate to find a woman to act as his personal manager, who follows up on all the numerous details and helps him communicate his wishes. Sam's disability makes it hard for him to follow conversation in group settings. For this reason, he did not attend circle meetings, preferring instead to be informed of the steps being taken on his behalf. His personal manager would relay to Sam what had been discussed and obtain his opinion about when and how to proceed.

Sam's financial status, difficult family relationships, and intensive support needs were a challenge to the people working to help him move out. Further, he wanted to live in a specific area of his hometown with which he was familiar. As the advocates explored options for Sam, they were continually struck by the lack of control, respect, and dignity he was experiencing in the institution. Sam felt that the nursing home was like a "prison camp" and rarely left his tiny room.

Finally, after 14 months of intensive work, Sam was able to leave the institution. A family member was able to buy a house for him in the area where he wanted to live. Sam was accepted for the Acquired Brain Injury Waiver. Still, arranging for the in-home supports he would need and satisfying the discharge requirements of the nursing home took many hours of planning and follow-up. Most of this work was done by the only person who could spend so much time on one individual, his personal manager. If it were not for her, Sam would still be sitting in his "prison camp."

Sam moved into his home, with its accessibility modifications also paid for by a family member, in June of 2000. Sam loves life in his new home. People come to visit him and he goes where he wants when he wants. His health has been good. Although there is a never-ending struggle to maintain enough staff, he is finally able to have the choice and dignity in his life that he deserves.

VI. ACTION STEPS

The title of this Plan is “Choices are for Everyone.” Choices require alternatives to institutions and information about those alternatives. As was stated in the Introduction, community options need to be expanded and people need to know about those options so they can make informed choices. The following action steps move Connecticut in the direction of additional supports in the community and better education of the general public, providers of services and supports, and people of all ages with disabilities. The action steps also address the barriers that were identified in Section IV of this plan: lack of public education about available options; lack of affordable and accessible housing; lack of assistance to persons with disabilities to help overcome fear, lack of experience, stigma, and the lasting effects of institutionalization or discrimination; lack of adequate and accessible supports in the community; and lack of a sufficiently large, competent, and adequately compensated workforce.

The Long-Term Care Planning Committee will oversee the implementation of these action steps, including developing a timetable for completion of the action steps and assignment of who will be responsible for each step. In addition, the Planning Committee will review this Plan on a regular basis and revise it as necessary.

Transition

1. Develop a system to identify individuals who are residing in institutional care (restrictive environments) and want to live in the community.
2. Review guardianship and conservatorship laws, regulations, and training to determine what revisions would be necessary to make them consistent with the independent living model.
3. Educate people with disabilities who are in institutions and who will be transitioning out, about the importance of working with a peer who has made a successful transition to the community. The peer can provide practical advice about how to prepare for and deal with many of the difficulties of living in the community and provide assistance once the person gets out. For example, when people first transition out of an institution, they may have no friends or relatives to help them in the community and/or they may have little to do. This can be depressing. In addition, in order to successfully work with personal assistants who

are not available 24-hours per day, people may need to train their bodies to be able to cope with the time periods between the personal assistance visits.

4. Explore the possibility of developing a peer support network for people transitioning from living in institutions to living in the community. This is important because adjustment to living in the community is more than getting the physical care or mental health services from a paid provider.
5. Educate people with disabilities that relying on paid support staff for 100 percent of their support needs will still leave them vulnerable. It is crucial to build on existing relationships where appropriate, and to develop strong new relationships with neighbors and members of the community.

Housing

1. Investigate how to improve the reporting of accessible housing units to the Connecticut Accessible Housing Registry. The current voluntary system has not produced the number of reported accessible units that are necessary for a successful registry.
2. Educate architects, housing authorities, builders, and local boards, such as planning and zoning commissions, about accessibility.
3. Convene a Task Force to review safety codes such as fire and building codes and recommend revisions designed to assure safety for individuals with functional limitations. Methods to follow-up and enforce these codes also needs to be reviewed.
4. Explore the possibility of providing tax or other incentives to encourage new homes or substantial renovations to meet minimum accessibility standards. This would apply to private homes as well as to public or private condominiums or apartments.
5. Strongly encourage every housing authority in the State to seek Section 8 certificates for people with disabilities when they are available.
6. Ensure that available Section 8 certificates are distributed to eligible families and individuals.

Supports

1. Increase the paraprofessional support workforce through the creation and implementation of a strategic marketing plan to recruit personal assistants and personal managers for permanent and backup employment.
2. Develop and implement a coordinated information source for backup personal assistants utilizing existing waiver program registries.
3. Encourage the “community team” (the team that comes together to assist the individual who is moving into the community) to continue to be involved with that individual for up to a year, if necessary, to deal with issues that could arise and increase the risk of re-institutionalization.
4. Work with Department of Labor to develop programs for displaced workers, clients of the Bureau of Rehabilitation Services, etc. to learn about personal assistance as a career.
5. Develop and make available optional training programs for individuals who want to support people with disabilities. Topics would include items such as meeting individual preferences of people with physical disabilities, meeting the special needs of individuals with mental health and mental retardation issues, communication with people who rely on non-verbal methods, and values associated with independent living.
6. Develop and implement training for people with disabilities who employ personal assistants regarding management of their employees. Management of employees includes hiring, coordinating personal assistants and their schedules, training personal assistants, completing the paperwork related to being an employer, working with a fiscal intermediary, developing and using effective relationship and communication skills, and terminating the employment of personal assistants when necessary.
7. Educate the public about the availability of services provided by the Department of Transportation and specifically how to access those services.
8. Analyze the fiscal impact of providing a Connecticut income tax deduction for medical expenses that are deductible under the federal income tax.

Community Connections

1. Distribute materials developed by the Nursing Facility Transition Grant to the general public, current residents of institutions, and providers of supports such as physicians and their office staffs, pharmacists and their support staffs, hospital personnel, builders, and plumbers.
2. Develop and implement training for people to become bridge builders, introducing people with disabilities to fellow community members who may become friends and support people.
3. Assure that translators, interpreters for the deaf, and those skilled in interpreting for individuals with cognitive or communication issues are available to provide information and assistance.

31 Years Old and in a Nursing Home

I am 31 years old. I had a stroke at the age of three and then again at age 26. This has left me totally disabled, with both sides affected and a complete loss of speech.

I had been getting therapy and have learned to stand with help. I also have a speech device, which I can use if my arms have range of motion done daily. I am able to type in messages and then my speech device verbalizes them.

I am forced to live in a nursing home because the hospital told me there was no other alternative. Living in a nursing home has taken away my dignity and quality of life.

I was eating pureed foods from 1996-1998, until I moved to another facility. Even though I can eat, this was taken away from me.

I want to have some control over my life. I want to choose the people I like to take care of me and not have to be in fear of who will be taking care of me next.

I hope to live in the community again, but there is not much available in the way of supports, transportation, or housing. I will need physical therapy, occupational therapy, and speech therapy. I will need 24-hour care. I will also need someone to make sure I have all these needs met, to handle emergencies, and so forth.

VII. CONCLUSION

The members of the Community Options Task Force, as well as several representatives from State agencies, have worked hard over the last two years to develop Connecticut's "Choices are for Everyone" Plan. The State representatives provided much of the background material on Existing Programs and Recent Initiatives that the State has implemented. The members of the Task Force developed the Principles and Stories. We have all worked together to clarify the Barriers to Community Integration and the Action Steps. Most important perhaps is the role the members of the Task Force have played in bringing the perspective of individuals with disabilities, representing all ages and all kinds of disabilities, to the forefront of discussions with State agency representatives.

As is illustrated in the Plan, there are numerous programs and services in Connecticut that serve to integrate individuals with disabilities into the community. Also illustrated is the fact that there are additional steps that need to be taken by the State to improve what already exists. This Plan is a starting point. Neither the members of the Community Options Task Force nor the State representatives want this Plan to be shelved and forgotten. This is a Plan in Progress and it will need to be reviewed and updated as necessary over the years.

APPENDIX A

THE COMMUNITY OPTIONS TASK FORCE

The Community Options Task Force (COTF) was a diverse group representing elders, persons with various disabilities of all ages, family members of persons with disabilities, and one representative from the Department of Social Services (DSS) who represents the State of Connecticut. Members were appointed jointly by the Commissioner of DSS and the Chair of the Long-Term Care (LTC) Planning Committee. Monthly meetings were chaired by a person with a disability from the Connecticut Council for Persons with Disabilities and the representative from DSS. The members of the COTF actively participated in the development of “Choices are for Everyone” since March of 2000. With the transmittal of this document to the LTC Planning Committee, the Task Force completed its mandate. Although the Task Force officially disbanded, many of its members will continue to work on issues of community integration through a variety of related committees, coalitions, councils, and task forces.

Community Options Task Force Membership (Inclusive of all members over the last two years)

Catherine D. Ludlum, CT Council for Persons with Disabilities; Co-Chair
Darlene O'Connor, DSS & LTC Planning Committee; Co-Chair (until Nov. 2000)
Linda J. Mead, DSS/State of Connecticut; Co-Chair (beginning in Nov. 2000)
Quincy Abbot, The Arc of CT (beginning April 2001)
Alberta Adams, Bloomfield (beginning July 2001)
Ethel Austin, Commission on Aging
Robert Board, Brain Injury Association of CT (until Nov. 2000)
Robert Cimiano, Alzheimer's Association
Molly Cole, Family Support Council
Edward Dale, Alternate to William Eddy (beginning July 2001)
Toni Dolan, Alternate to Therese Nadeau (beginning Oct. 2001)
William Eddy, American Association of Retired People
John Esteves, Valley Disability/CT Job Works
Nicolle Geiling, Fairfield (beginning July 2001)
Claude Holcomb, ADAPT of Connecticut
Mary Ellen Kampfman, Brain Injury Association of CT (beginning Nov. 2000)
Fritzie Levine, Parents & Friends LFC & Assoc. Group Homes (until April 2001)
Candace Low, Independence Unlimited (beginning Oct. 2001)

Laura Micklus, CT Women & Disability Network
Tom McCann, Manchester (until Nov. 2000)
Therese Nadeau, Co-op Initiatives
Carolyn Newcombe, Disabilities Network of Eastern CT
Barbara Ortique, Bloomfield (beginning July 2001)
Susan Raimondo, Family member of someone with MS (beginning April 2001)
Nanette Serrano, American School for the Deaf (Nov 2000 until Oct. 2001)
May Terry, Representing People with Psychiatric Disabilities
Michael Valuckas, State Independent Living Council

APPENDIX B

THE PLANNING PROCESS FOR “CHOICES ARE FOR EVERYONE”

1. The Department of Social Services (DSS)

With the support of the Governor, and on behalf of the Long-Term Care Planning Committee, DSS initiated activities in January of 2000 to develop a comprehensive plan for community integration of persons with disabilities. DSS was viewed as the appropriate agency to lead these efforts because it is both the Medicaid agency for Connecticut and the lead agency for persons with disabilities, as identified in State law.¹⁰ DSS has coordinated the planning in this area with other State agencies, persons with disabilities, providers, other advocates and legislators.

2. The Long-Term Care (LTC) Planning Committee

In 1998, the Connecticut General Assembly established the LTC Planning Committee,¹¹ creating a forum for State agencies to better coordinate their long-term care planning efforts for older persons. The Committee was charged with developing a plan for long-term care services. It issued a Preliminary Plan in 1999. In early 2000, when the State decided to focus on the unique issues raised by the Americans with Disabilities Act and the Supreme Court’s Olmstead decision, it turned to the Committee. The Committee, in conjunction with DSS, established a separate task force on community options, thereby tasking a diverse group of persons with disabilities to begin working on a comprehensive plan to support community options for all people in need of long-term care. That group

¹⁰ DSS is a multi-faceted human services agency which includes administration of the Medicaid program, services for older persons, services for persons with disabilities, welfare benefits, and other related programs. The agency is designated under state law as the lead agency for persons with disabilities. The Connecticut Council for Persons with Disabilities is an advisory body made up of people with disabilities and advocates, and provides input to the Commissioner of DSS. In addition, DSS has two representatives on the LTC Planning Committee.

¹¹ The LTC Planning Committee is a joint executive/legislative branch committee. Initially the membership included the Chairs and Ranking members of the General Assembly’s Committees on Human Services, Public Health, and Aging, as well as representatives from the following state agencies: Social Services (including aging, disability and family services), Mental Retardation, Mental Health and Addiction Services, Public Health, Economic and Community Development, Transportation, the Office of Health Care Access, the Office of Policy and Management, and, on an ad hoc basis, the Department of Children and Families.

became the Community Options Task Force (COTF), described more fully in Appendix A .

The legislative mandate for the LTC Planning Committee has since been expanded to include all persons in need of long-term care, not just the elderly. Effective July 1, 2001, the LTC Planning Committee is charged to plan for all persons in need of long-term care. The Committee must “evaluate issues relative to long-term care in light of the United States Supreme Court decision in *Olmstead v. L.C.*, 119 S.Ct. 2176 (1999), requiring states to place persons with disabilities in community settings rather than in institutions when such placement is appropriate, the transfer to a less restrictive setting is not opposed by such persons and such placement can be reasonably accommodated.”¹² The Committee’s membership has been expanded to reflect its larger mission.¹³

The Long-Term Care Planning Committee Membership

First Name	Last Name	State Agency/Organization
David	Guttchen	Office of Policy and Management
Lisa	Rivers	Department of Transportation
Wendy	Furniss	Department of Public Health
Michele	Parsons	Department of Social Services
Christine	Lewis	Department of Social Services
Andrew	Wagner	Department of Mental Retardation
Rick	Robbins	Dept of Economic and Community Development
MaryAnn	Lewis	Office of Health Care Access
Jennifer	Glick	Dept of Mental Health and Addiction Services
Lou	Ando	Department of Children & Families
Stan	Kosloski	Office of Protection and Advocacy
Senator Edith	Prague	Select Committee on Aging
Representative Peter	Villano	Select Committee on Aging
Representative Terri	Gerratana	Human Services Committee
Senator Mary Ann	Handley	Human Services Committee
Representative Pat	Shea	Human Services Committee
Senator Toni	Harp	Public Health Committee

¹² Public Act 01-119 (2001).

¹³ Membership was expanded to include representatives from the Department of Children and Families and the Office of Protection and Advocacy for Persons with Disabilities.

Senator George	Gunther	Public Health Committee
Representative Dennis	Cleary	Public Health Committee
Senator Cathy	Cook	Human Services Committee
Representative Anthony	D'Amelio	Select Committee on Aging
Senator John	Kissel	Select Committee on Aging
Representative Mary	Eberle	Public Health Committee

3. The Long-Term Care Advisory Council

The LTC Advisory Council was established to advise the LTC Planning Committee on its original charge -- to plan for the full range of long-term care needs of older persons (including institutional, community and housing services). The Advisory Council includes representatives of long-term care providers and employees, advocates, and older persons. Because the mission of the LTC Planning Committee has been expanded to include all persons in need of long-term care, membership on the Advisory Council will likewise need to be expanded. There is now a legislative proposal to include, as members, three people with disabilities, a caretaker of a person with a disability, the president of the Family Support Council or designee, a personal care attendant, a nonunion home health aide, and a legislator who is a member of the LTC Planning Committee.

The Long-Term Advisory Council Membership

First Name	Peter	State Agency/Organization
Peter	Villano	Select Committee on Aging
Julia	Evans Starr	Commission on Aging
Margaret	Morelli	Connecticut Association of Non-Profit Providers for the Aging
Randall	Bernstein	Coalition of Presidents of Resident Councils
Teresa	Cusano	Department of Social Services
William	Eddy	AARP Capitol City Task Force
Eleanor	Prouty	District 1199 AFL-CIO
Marilyn	Denny	Greater Hartford Legal Assistance
Marjorie	Anderson	Connecticut Association of Residential Care Homes
Toni	Fatone	Connecticut Association of Health Care Facilities

Rob	Board	Connecticut Council for Persons with Disabilities
Molly	Gavin	Connecticut Community Care, Inc.
Joanne	Byrne	Connecticut Association of Area Agencies on Aging
Jennifer	Jackson	Connecticut Hospital Association
Virginia	Humphrey	Connecticut Home Care Association
Lynda	Moecker	Connecticut Alzheimer's Association
Denise	Cesareo	Connecticut Association of Adult Day Centers
Teri	Golec	American College of Health Care Administrators
Chris	Carter	Connecticut Assisted Living Association
Joelen	Gates	Connecticut Legal Services
Paul	Puzzo	Connecticut Association of Community Action Agencies

4. The Olmstead Coalition

A coalition of persons with disabilities, known as the Olmstead Coalition, organized itself in January 2000, just as the State was beginning to launch its planning process. Members of the Olmstead Coalition meet regularly, and communicate more frequently through an electronic list-serve. The Coalition has found this means of communication to be a quick and effective way to disseminate information throughout its network. Several members of the Olmstead Coalition are members of the Connecticut COTF, resulting in regular communication between the Coalition and the COTF.

5. Informal Forums, Public Hearings and Meetings

It was recognized that advice on the comprehensive plan had to be solicited from an even broader community than the above-mentioned formalized groups. Therefore, various organizations were encouraged to conduct forums with their members in order to broaden the input on the plan. These have been informal discussion sessions in which individuals were able to raise issues of concern related to the planning of community services. Organizations that have held forums include:

- The Long-Term Care Advisory Council - May 31, 2000
- The Commission on Latino and Puerto Rican Affairs - June 22, 2000
- The Western Agency on Aging and Independence Northwest
- August 9, 2000

- The South Central Agency on Aging and The Center for Disability Rights - August 16, 2000
- The Connecticut Council for Persons with Disabilities - August 2000

In the fall of 2000, following the release of the third draft of the plan, six public hearings were held in various parts of the State.¹⁴ At each hearing there was a representative from the LTC Planning Committee and at least one representative from the COTF. The dates and locations of these hearings were as follows:

- Waterbury, Connecticut - October 26, 2000
- Hartford, Connecticut - October 27, 2000
- Westport, Connecticut - October 30, 2000
- Meriden, Connecticut - October 31, 2000
- Norwich, Connecticut - November 1, 2000
- Rocky Hill, Connecticut - December 12, 2000

In addition to these informal forums and public hearings, which were held specifically on the development of the plan, other public gatherings have occurred. Most notably, with the announcement of the “Systems Change Grants for Community Living” in the winter of 2000-2001, Connecticut’s community of persons with disabilities came together to discuss the grant applications. The Olmstead Coalition, in collaboration with several other organizations, hosted an all day forum on April 9, 2001, to identify issues the participants wanted addressed in the State’s grant applications. An outgrowth of that forum was the formation of the Real Choice Task Force, which worked with the State in development of the grant proposals. The members of the COTF formed the base of the Real Choice Task Force and other individuals were added to assure an even broader representation. Since many of the issues were the same in the Olmstead Plan and the grant applications, this process gave the State further input from the community

¹⁴ The Report on the Public Hearings that was presented to the Long-Term Care Planning Committee is in Appendix C. The Comments and Questions Raised at the Public Hearings is in Appendix D.

of persons with disabilities. Notably, the parameters that the Real Choice Task Force and the State agency representatives used when reviewing concepts for the grant applications were kept in mind when the Community Options Task Force evaluated ideas for Connecticut's Olmstead Plan. The parameters required that grant projects had to:

- Benefit all people with disabilities;
- Be consumer/person directed;
- Provide a continuum across a life span;
- Increase flexibility and choice;
- Address cultural competency;
- Result in enduring change; and
- Assure sustainability

APPENDIX C
REPORT
ON PUBLIC HEARINGS HELD THROUGHOUT
CONNECTICUT
October 26 – November 1, 2000

Regarding the Third Draft of
Choices Are for Everyone
(Also called the Olmstead Plan or the Community Integration Plan)

Presented by Cathy Ludlum, Co-Chair, Community Options Task Force,
to the Long-Term Care Planning Committee, November 15, 2000

General Overview and Scope of Hearings

Public hearings were recently held to receive comments on the third version of the Olmstead Plan, *Choices Are For Everyone*. The hearings took place in Waterbury, Hartford, Westport, Meriden, and Norwich.

At each hearing, there was a representative from the Long-Term Care Planning Committee and a representative from the Connecticut Community Options Task Force. At several of the hearings, there were additional members from these two groups.

Approximately 35 people offered testimony over the five days, and approximately 86 members of the general public came to listen. These numbers are not precise because some people did not sign in, and some people chose to testify at the end without signing up.

Those of us who were there to listen to the testimony were pleased with the turnout, and found the testimony interesting and enlightening.

Testimony and Its Relationship to Priorities Already Identified

Shortage of accessible and affordable housing came up over and over again, both as a "poverty" issue (people receive so little money that they can barely afford to live) and as a housing issue (accessible housing is scarce, and all housing is

expensive). The lack of appropriate housing too often forces people into shelters or into institutions.

This links to Priority D-1¹⁵ which recommends raising the rental allowance under Supplemental Security Income (SSI) to a more realistic rate.

It also links to D-2, which calls for increasing the amount of accessible and affordable housing in Connecticut, and D-3, which recommends diversity of housing types to accommodate different living situations.

We heard stories of public/private partnerships, especially around innovative housing models, that allowed people to live in safety and autonomy.

These are tied to B-1 and F-3, which speak to the importance of transitional living options and establishing strong partnerships between the public and private sectors.

We heard from many different populations, sometimes needing very different types of support. What works for one person will not necessarily work for someone else.

In Westport and Norwich, in particular, there were many stories from people with psychiatric issues regarding the supports they need to live successfully in the community. One asked, "How bad do things have to get before we can get some support? Doesn't it make more sense to give people the support they need when they are doing well so that the worst case scenarios can be avoided?"

We also heard stories of fragmentation within and between State departments and programs. Sometimes the conflicting requirements cause people to fall through the cracks so they do not receive the support they need to live in the community. People spoke of being discriminated against because they were too old, too young, too well, or had the wrong disability label to receive the needed services.

All of these points link to F-1, which calls for replacing funding streams that put people into slots with a new system of individualized budgets that take into account the differing needs of each person.

They also relate to E-2 and E-3, which point to the limitations of Connecticut's existing Medicaid waivers. Present waivers are designed according to age and diagnosis, when there is a real need to look at what individuals can or cannot do for themselves.

¹⁵ Please see Appendix F for these Priorities.

Transitioning onto one's own is never easy, not for people without disabilities, and certainly not for people who have additional challenges. Several people who testified had been in and out of institutions several times because there was not adequate support in the community.

One type of support which seems to be lacking is assistance with coordination of staffing, paying bills, keeping track of appointments, and related management-type tasks.

This is tied to E-1, recommending services of a personal manager to be made available through one or more of Connecticut's Medicaid waivers.

Another obstacle is lack of experience and fear about living outside of the institution.

This links to B-3, which would increase support to Independent Living Centers to work with people with disabilities to teach them the skills necessary to succeed in the community.

Yet another obstacle that people spoke about was the lack of adequate transportation.

This links to all three recommendations under Section C of the priorities list. At present, many people are only able to access transportation to medical appointments and (if they are children) to school. Creation of more individualized options that make use of existing systems and create new jobs are necessary to allow people to have a life.

Ultimately, community integration will not happen unless people with disabilities have enough capable support people in their lives. Individuals and community providers spoke to the shortage of personal assistants, home health aids, and other direct support workers. There was testimony about home health agencies dropping services to people because of reduced Medicare rates and unrealistic backup plans.

The recommendations under Section G, aimed at adequate pay, benefits, and esteem for direct support workers are targeted at solving these issues. In setting the State's priorities for spending, how can one argue that giving fair compensation for good care is not a good investment?

Finally, there was a consistent theme of concern that Connecticut's Olmstead Plan not be simply a nice document of good ideas, but that it be FUNDED and IMPLEMENTED so that its stated goals can be achieved. There was a call for target numbers and dates to transform the concepts into realities in the lives of

real people. Someone said that we need targets in order to measure our successes. Many people said that a lack of target numbers for deinstitutionalization equates to a lack of commitment by the State to community integration.

This theme is tied to priority F-2, which calls for a permanent State commitment of resources to support community integration efforts. The State needs to do more than commit to the philosophy of the Olmstead Plan; it needs to back it with funding.

People need real choices. Institutionalization cannot be the only alternative.

APPENDIX D

COMMENTS AND QUESTIONS Raised at PUBLIC HEARINGS and FORUM October 26 - December 12, 2000

Regarding the Third Draft of *Choices are for Everyone*

A. COMMENTS

1. Several comments were made concerning the specific content of the Plan.

We need a concrete plan of action to actually move people out of institutions and to create the community supports needed to keep people from being placed in institutions. (Several comments.)

The Plan should include target numbers of people to transition out of institutions (and the budget numbers needed to make that happen) and timelines for these people moving into the community. (Several comments.)

There must be a financial commitment from the State to implement the Plan, including funding the transition of people from institutions into the community; funding for adequate community-based support services; and funding for accessible, affordable and supportive housing. (Several comments.)

The Plan needs financial backing and a higher priority within the State.

The Olmstead decision discusses waiting lists of people wanting to transition into the community from institutions and the importance of moving through these waiting lists at a reasonable pace. This issue of waiting lists needs to be addressed in the Plan.

State agencies with programs that affect people with disabilities should each have a budget line for Olmstead provisions. There is concern that Connecticut's budget

cap may be used as an excuse to avoid responsibilities in the Olmstead decision. If the budget cap is a problem, it must be re-addressed.

The Plan should incorporate the findings and recommendations of the Blue Ribbon Commission on Mental Health. (Several comments.)

The Plan should take into account the additional and specialized resources that will be needed to transition people with mental retardation and other developmental disabilities into the community.

The Plan needs to address inappropriate institutionalization in correctional facilities and shelters.

The Plan should mention the pilot peer engagement specialist program that DMHAS is implementing. This is considered to be a national model.

Connecticut should spend whatever is necessary to comply with the Olmstead decision.

Even if the Garrett decision undermines the Olmstead decision, Connecticut should move forward with a community integration plan.

There are two barriers that the draft Plan did not address: (1) The program barrier (some programs do not include in their benefits the basics for people to access the other benefits, i.e., personal managers to assist individuals in staffing their care plans); and (2) The economic barrier (some programs require people to live in extreme poverty, when receiving a livable income is fundamental to a person's access to opportunity and choice).

The EMPOWER planning process for individuals now living at Southbury Training School does not meet the test of the Olmstead decision and must be replaced. Under EMPOWER, guardians, rather than the individuals with disabilities themselves, may reject even the consideration of a move to the community.

2. Several comments were made on issues that the Plan had already identified, thereby reinforcing the goals and priorities that the Task Force had set out. In addition, many people praised and thanked the Task Force members.

Education about Disabilities and Community Options

People who are at risk of institutionalization or who are already institutionalized should be given sufficient information about community options before they are asked to decide whether to choose community placement or not.

Families should be educated about community options and should be brought into the process when their family members are being considered for community placement so that they can advocate for them.

Information about the availability of community-based support services and agencies to assist in the transition from living in an institution to community living, both general and person specific, should go to families as well as the individual who is disabled. (Although the decision about where to live should be made by the individual who is disabled.)

An education program needs to be developed and implemented. The public needs to be educated about disabilities, including invisible disabilities, such as brain injury, and psychiatric and learning disabilities.

The public must be educated about people with disabilities. People with disabilities are regular people who happen to have disabilities and they should not be treated like second-class citizens. Some people with disabilities keep themselves isolated so they will not be subject to unkind comments, insults, and day-to-day discrimination.

It is especially important to educate teachers about the problems people with disabilities face living in the community and what community support services are available. Many children with disabilities are mainstreamed in schools these days and teachers need to prepare them for living their lives in the community. Some of the information for the public should be on tapes for those of us who cannot read.

Adequate and Available Transportation

There needs to be a more effective transportation system for people with disabilities. (Several comments.)

More accessible transportation is necessary, and information on existing transportation needs to be better disseminated to people with disabilities, social workers at institutions, and the general public.

Adequate and Available Housing

There needs to be more affordable, accessible, and safe housing in the community. Additionally, more supportive housing for people with psychiatric disabilities is necessary.

People with disabilities need decent and safe housing. There is a need to develop shared housing.

Finding housing that is accessible and affordable is a problem. And even when an apartment or home is “wheelchair accessible” that does not always mean that it can accommodate all wheelchairs. Some wheelchairs are bigger than others.

There needs to be money available for modifications to existing homes in which families reside. There needs to be more accessible, affordable and safe housing for families with children.

The Need for Community Supports and Services, Including New Options for Community Integration

The Plan’s goal of increasing adult day care and home care rates is important for continuing to provide community supports. The new “Ticket to Work” program is especially welcome.

More State money needs to be spent on community-based facilities and programs to help people stay home and not go into nursing facilities. Less State money should be spent on the nursing facilities themselves.

The Medicare rules, which were changed October 2000, give less leeway to home care agencies in how much care they can provide. The effects of this have already been felt. Home care agencies are not taking new clients as quickly, even if they have been prior clients. Thus, people have fewer options for the community support they need in order to live in the community.

The decline in community mental health services, especially for the elderly, needs to be addressed.

There is no one “system of support” for people with disabilities. The present services are fragmented throughout State agencies and across differing eligibility requirements. The complexities of eligibility and benefits are confusing. Even when the interrelationship of programs is understood, the system is still too hard to navigate. Some people just give up.

There is gridlock in the provision of health care in the community. Care is not being provided and people are ending up in shelters and jails.

There is a need for outpatient psychiatric care.

There needs to be flexibility in programs, and people’s lives should not be upended when they have to move from one program to another to accommodate changing physical and/or psychological needs. People with disabilities, like everyone, need stability in their lives.

Connecticut’s spending cap is a barrier to community integration.

The present system of programs facilitates institutionalization. This needs to be reversed.

Real community supports are necessary. The goal is for people not only to live in the community, but also to thrive in the community.

Community supports should include training and assistance with hiring, firing, and training personal care attendants.

We need more community-based support services and the programs that make these services available should complement each other, not work at odds with each other.

We need to recognize that some people, especially those with a psychiatric disability, have ongoing issues even during times when they may appear to be doing well in the community. These people must continue to have access to community-based support services even when they are doing well so that when a need arises they can deal with it expeditiously and are not thrown into a crisis.

Nursing homes must not be allowed to become the new institutions for people with psychiatric disabilities. Of the people under age 65 who live in nursing homes, 40 percent are people labeled with mental illness.

Community-based support services are needed in all towns. There needs to be more day care, extended day care, and respite services; assistance with the transition from living in an institution to living in the community; and family support.

Community supports for people with brain injuries need to be continual and flexible because physical and cognitive conditions are ever changing. People with brain injuries may need support services in life skills, including parenting.

The personal care assistance waiver should not be limited to hands-on care.

The Need for a Sufficiently Large, Competent Workforce

We need to find a way to attract and retain competent people to provide the community support that is necessary for so many persons with disabilities to live in the community. Major increases in wages and benefits for personal assistants, home health aides, and other direct support workers will help significantly. The work they do needs to be valued by society. (Several comments.)

The amount of money allowed by the waiver is not enough money to hire personal assistants.

It is sometimes difficult for the person with the disability to hire, fire and train his or her own personal assistants. Persons with disabilities may need ongoing assistance in hiring and managing their staffs.

Kudos

The Plan is comprehensive. There are a lot of excellent suggestions in it, especially regarding housing and transportation.

Thank you (to the members of the Task Force) for all the work you have done. It is not easy to come up with a comprehensive plan that encompasses all groups of people with disabilities.

We appreciate all the hard work the Task Force has done. We know that it has been a difficult task because the issue of community integration is so comprehensive.

Kudos to the Task Force for all the work the members have done to develop the Plan. The Plan embraces the ideas that everyone belongs and everyone should have choices.

B. QUESTIONS

Q. How much does it cost to transition from an institutional setting to the community?

A. *There is a committee of the Olmstead Coalition researching the average cost.*

Q. Is there a resource book available to assist in the transition process from living in an institution to living in the community?

A. *We are unaware of such a guide, but clearly, such a resource would be extremely helpful.*

Q. How can we make the Plan available to someone in an institution without negatively affecting the care provided or otherwise compromising that person's rights?

A. *Two of the major priorities of the Plan are the need to address (1) the lack of public education and awareness and (2) the lack of assistance to overcome fear and discrimination. If those priorities are effectively addressed in the future, people in institutions should not have to worry that possessing information about ways to transition to the community will negatively affect their current living circumstances in any way.*

Q. How do we help people deinstitutionalize?

A. *We believe this Plan will have significant impact on the Governor and Legislature, especially if it is seen as the collaborative effort of persons with disabilities, families of persons with disabilities, State agencies, legislators, and other interested stakeholders. In the long run, we expect the Plan will facilitate deinstitutionalization.*

Q. Why does the Long Term Care (LTC) Planning committee get to choose what parts of the plan get to go forward and not the Community Options Task Force, which is represented by people with disabilities?

A. *The Plan is being developed collaboratively by the Task Force, the LTC Advisory Council, the LTC Planning Committee, and by interested stakeholders who have commented on the various drafts of the document. While the LTC Planning Committee is overseeing the planning process, its role is not to decide on its own what parts of the Plan are included. That process is a collaborative one with all the parties just noted. With such broad-based involvement, the Plan's impact on policy makers should be significant.*

Q. Why was the Plan developed for consumers instead of by consumers?

A. *The Plan has been developed in large part by the Task Force, although it is a collaborative effort. The Task Force membership is as follows: 53 percent representation by people with disabilities; 46 percent representation by people who are advocates of persons with disabilities (many of whom also happen to have disabilities themselves); and 1 percent representation (or one person) from a state agency.*

Q. Why are there differences between various State programs that appear to provide disincentives and barriers for individuals to receive necessary services in the community?

A. *Through the planning process, with the help of the Task Force and other stakeholders, several barriers to community services have been identified, including the differences between various State programs. Some of the differences between programs are dictated by federal law and others are under the State's control. One of the goals of the Plan is to examine barriers such as these and to determine what changes the State can institute in order to encourage the expansion of community-based options. Two examples of how the State has already worked to break down some of these barriers are (1) the income expansion of the Connecticut Home Care Program for Elders and (2) the "Ticket to Work" program which will allow individuals with disabilities to earn up to \$75,000 per year and still retain their Medicaid coverage.*

APPENDIX E

BARRIERS to COMMUNITY INTEGRATION Identified by Persons with Disabilities and Other Stakeholders Fall 2000

As part of the development of this plan, a variety of persons with disabilities, advocates, providers and other stakeholders raised concerns and issues. The Connecticut Community Options Task Force held several brainstorming sessions to identify barriers to community integration and possible solutions. In addition, members of the Olmstead Coalition established workgroups to develop issue papers articulating concerns and possible options. Finally, through meetings with individual groups and through public forums, the State gathered additional suggestions.

The following list of barriers represents a compilation of the possible barriers identified by stakeholders through these various processes. The list is an attempt to articulate all the issues raised so that the State can review and consider them, not to affirm or rank their importance. In some cases, issues raised by one group may be inconsistent with issues supported by other groups. Inclusion of this list within the State's planning document is not an acknowledgement by the State that the barriers are problems for all persons with disabilities in Connecticut, but rather a reflection of the perception of stakeholders on these issues.

1. Lack of Public Education and Awareness

Public education is the first step toward public support for community integration. Public support will not be forthcoming unless education and awareness are present first. The general public should be better informed regarding programs and options that promote community integration for its disabled citizens.

- a. Public and private service agencies do not always have sufficient information regarding the options and programs available to the disabled citizens they serve.
- b. The media (radio, television, newspapers, etc.) are not always updated regarding programs and issues. If they are not advised, they cannot present them to the public. Also, success stories are rarely publicized.

c. Institutions, such as hospitals and nursing facilities, do not always keep their staffs informed regarding programs to facilitate community integration. If uninformed, staff members cannot communicate updated information regarding community options and supports to residents and their families. Such education would enable institutions to be more receptive to allowing increased access to the individuals who reside in their institutions. The roles of advocates, ombudsmen, and other interested parties are not always understood and may need to be expanded to assist in facilitating greater access to residents.

d. Landlords and real estate agencies are not sufficiently aware of the housing needs of the disabled population or of subsidy/incentive programs available to them.

e. Community neighborhoods and religious communities do not always have contact with disabled citizens. Neighbors are not sufficiently educated to enable them to dispel negative stereotypes and/or to overcome their fears of disabled individuals. In particular, there is insufficient understanding and acceptance of persons with mental illness and those dually diagnosed in order to overcome the stigma widely associated with these particular disabilities. School integration and recreational activities, neighborhood playgrounds, community centers and gatherings are often not geared toward inclusion of all disabled individuals and/or their families. Insufficient inclusion in various community educational and social activities makes it difficult to educate the general public and to breakdown old misconceptions and barriers. There is inadequate education for students, teachers and administrators in the public schools on disability issues. Appropriate education on disability issues could be included in diversity training programs and would then “spill over” to the home, neighborhood, and community.

f. Physician education is critical and currently insufficient. A physician’s view/opinion can preclude access to community options, yet physicians may not know what is possible for their patients to accomplish or what options are available to them. Because they tend to often treat an individual based solely on an established medical model, physicians may overprescribe medications at times. Without a physician’s approval a person often cannot get access to funding. The time allotted for physician’s appointments often does not enable the doctor to get to know the person with disabilities and to understand their situation, abilities, and plans. Physicians need to be educated so that they are able to be more appropriately involved in the treatment of the complete person

in a more appropriate manner and not simply focus on individual conditions and symptoms.

g. Individuals with disabilities need to understand their own abilities and needs and be empowered to recommend treatment when appropriate.

h. Parents and guardians of individuals with disabilities are not sufficiently aware of all the options available and need information about the necessary supports so that they can in turn help the person with a disability to speak for themselves and make their own decisions whenever possible. This is particularly true for parents whose primary language is not English.

2. Lack of Affordable and Accessible Housing

There is not sufficient, affordable, and accessible housing (rental and owned) in Connecticut. Funding of and access to grants and programs for implementation of modifications, subsidized rental, and home ownership programs is insufficient to meet the needs of our disabled adults as well as disabled children and their families. Housing programs do not have enough funding for home modifications. There are no deep subsidies to support home ownership.

3. Lack of Assistance to Persons with Disabilities to Overcome Fear, Stigma, and Discrimination

The fears, stigma and discrimination that a person with a disability is faced with when transitioning from an institution to the community may at times appear overwhelming. These issues could prove to be the biggest barriers for persons with disabilities to overcome in order to succeed in community placement.

a. Institutions do not always provide encouragement, information, or transition support to residents and/or their families regarding community options and programs. Persons with communication or language difficulties have an additional stigma that adds to this barrier.

b. Waiver programs often provide only select services or have age restrictions for participation. These limitations keep services from being continued or available in some cases. This only adds to the uncertainty and fears of those individuals and/or their families.

c. Individuals with disabilities in the community may not have sufficient access to work with and support institutionalized persons and/or their families in transitioning to the community. Encouragement and understanding have not always been readily available from individuals who are dealing successfully with the fears, stigmas, and discrimination that are often present when transitioning to and living in the community.

d. Persons with disabilities and/or their families are not always involved in all aspects of planning for community placement. This prevents them from having a sense of ownership and the opportunity to build self-confidence in their ability to make the transition to community living.

e. The lack of coordination of all supportive and service delivery systems, especially those involving children with disabilities, often results in poor communication and confusion. Such lack of coordination may also reinforce individual fears.

f. There is a lack of sufficient assistance to enable persons who have been institutionalized to learn skills to live in the community, to learn how to make choices well, and to overcome the lack of experience in living in the community.

4. Lack of Adequate and Available Community Supports

Specific supports in critical areas are not always in place in order for community integration to succeed. These community resources are necessary for both activities of daily living as well as to improve one's quality of life. The lack of available supports is even more significant for individuals facing communication or language barriers.

a. Transportation: There is not adequate and accessible public transportation seven days a week in order for Connecticut's disabled population to make and keep appointments, attend religious and community functions, and recreational activities. This need also exists for some service providers who rely on public transportation. Employees may have to limit their days and hours of employment if they rely on public transportation. There is also insufficient access to and minimal subsidy of private transportation providers. Additionally, there is frequently a low level of funding for vehicle adaptations for disabled individuals and/or their families, which may limit community

involvement and integration. In some rural areas of the State, public transportation does not exist.

b. Programs: Government and private community-based programs may not be supporting community options where appropriate. Some, but by no means all, of the issues in need of review are:

- State sponsored programs are too limited and do not place their focus on the total needs of an individual but just on the medical needs. Generally, programs tend to focus on established treatment models and not personal choices. Programs are not sufficiently individualized or person centered. Current gaps include specialized day care for individuals diagnosed with Alzheimer's Disease, programs that address the needs of persons with dual diagnoses, and jail diversion programs. Additionally, the State's Personal Care Assistance Waiver, does not allow participants access to the direct pay option.
- Programs currently require too many authorizations and unnecessarily long timeframes before goods and services can be received. For example, access to durable medical equipment is cumbersome.
- Programs and insurance policies often do not allow an individual to supplement funding (such as Medicaid) with private funds in order to obtain goods and services. Additionally, there is insufficient information regarding what goods and services are covered under both public and private programs and insurance.
- Community-based programs have eligibility requirements that may create incentives for institutionalization. For example, when applying for certain programs, a person may be penalized for shared expenses with a housemate/roommate or a spouse. Also, life insurance is counted as an asset when determining eligibility and may prevent planning for long-term needs.
- There is inequity in funding across various State agencies such as the Departments of Mental Health and Addiction Services, Social Services, Children and Families, and Mental Retardation.

- Many community programs require a person to be “safe” as a condition of eligibility. Such requirements often leave individuals without control to determine what constitutes “safe” for them.

c. Employment: There are insufficient competitive employment opportunities, including opportunities for assessment and training for employment and employment related services. Consequently, many people with disabilities are not gainfully employed.

d. Public Education: Many Connecticut school systems have insufficient resources for intervention and assistance to enable them to work more successfully with students with disabilities and/or their families. There is not enough focus on classroom inclusion, as well as adapted recreational activities. Schools need to cease “segregating” students by keeping them out of the mainstream. There are not enough supports for children with disabilities in schools.

5. Lack of a Sufficiently Large, Competent, and Adequately Compensated Workforce

The lack of a sufficiently large, competent, and adequately compensated work force is a major barrier to community integration and impacts delivery of service to our citizens with disabilities. Competence includes having the requisite technical skills, understanding disability issues, being culturally knowledgeable, and having the ability to communicate with individuals in ways that they understand.

- a. Persons seeking employment are not always aware of the employment opportunities with persons with disabilities. Employers also do not reach out to persons with disabilities as potential employees.
- b. It is difficult to compete with the lure of institutional employment where higher salaries and better benefits prevail. For example, the number of hours one is allowed to work, as well as the pay and benefits available to community personal assistants, are not comparable to those employed in a similar position in nursing facilities and hospitals. In fact, personal assistants generally have no health insurance and no worker’s compensation insurance.
- c. There are fewer people entering the health care field and more people leaving it in part due to better benefits in other employment arenas. Today, benefit packages are often as important as salaries when one is considering

employment options and benefits are often not available for entry level health and social service positions.

d. A low pay scale exists for many employees in the health care field. As a result, this field has in some cases attracted less qualified and less reliable individuals.

e. The private sector as well as state and federal government reimbursement rates are perceived as too low for health care providers. Additionally, reimbursement is not always made in a timely manner.

f. Some persons with disabilities would like to have increased support for coordination, through the use of personal managers.

g. There is no “back up” registry for qualified health care staff, especially for personal assistants, to enable persons with disabilities to maintain continuity of support.

APPENDIX F

COMMUNITY-BASED SUPPORT PRIORITIES Identified by Persons with Disabilities and Other Stakeholders Fall 2000

A. Address Lack of Public Education and Awareness

1. Develop a coherent outreach campaign about disability issues and home care including materials on community options for physicians, nursing facilities, hospitals and service agencies.
2. Reach people at risk of institutionalization and brainstorm alternative solutions with assistance from advocacy groups. Collaborate with nursing facilities to open doors to advocates. Make persons with disabilities, parents and guardians aware of all the options (keeping in mind that institutional options should still be available).
3. Assure that translators are available to provide information and assistance.

B. Address Lack of Assistance to Overcome Fear and Discrimination

1. Offer transition assistance to persons seeking to leave institutions.
2. Provide ongoing transition support to individuals for at least one year after they leave institutions.
3. Increase funding for Independent Living Center staff to work with nursing facility residents on the Activities of Daily Living (ADL) skills training to live in the community and in developing circles of support.

C. Address Lack of Adequate and Available Transportation

1. Make accessible transportation available for purposes other than medical and educational purposes.
2. Create a subsidy to hire someone for accessible transportation.

3. Change DOT policy so that financial assistance and vehicles are given to local transit districts for the creation of accessible, affordable and convenient transportation.

D. Address Lack of Adequate and Available Housing

1. Raise the current rent limit for the State Supplement to SSI to a more realistic amount.
2. Implement both long-term and short-term plans for increasing affordable, accessible housing. Expand the Medicaid home and community-based services to include accessibility modifications for all eligible persons.
3. Plan for diverse housing needs including housing for persons with disabilities living with families, children, or other live-in partners.

E. Address Lack of Other Community Supports and Services

1. Cover personal manager services under one or more waivers.
2. Cover additional waiver services for younger persons with disabilities (e.g., home delivered meals, emergency response systems, adult day health services).
3. Cover personal assistance services as a Medicaid State Plan service or add personal assistance services under all waivers.

F. Address Other Service-Related Issues

1. Convert existing funding streams for supports and services from those in which people are "slotted" and "segregated" into funding streams that are assigned to each individual needing support.
2. Establish a permanent commitment of State (including Medicaid) resources to support community integration efforts.

3. Encourage the development of public/private partnerships to increase opportunities and choice for persons with disabilities.

G. Address Lack of Sufficiently Large, Competent Workforce

1. Increase pay scales for personal assistants and other support workers.
2. Offer benefits (health care, vacation time) to personal assistants.
3. Treat Personal Assistance (and other support work) as a valued occupation and provide some career growth possibilities. Conduct public education to communicate the value of this work and to help recruitment.

APPENDIX G

CONNECTICUT'S PLANNING for COMMUNITY ALTERNATIVES

Like most states, Connecticut has been gradually shifting the focus from institutional to community services. In the late 1980s, prior to the passage of the ADA, the former Department of Human Resources developed a *State Plan on Disabilities*. This document was developed in collaboration with persons with disabilities and representatives of all relevant State agencies. This plan established a “foundation for the future” which has supported the expansion of home and community-based services through the 1990s. The *State Plan on Disabilities* included a chapter entitled the “policy framework” which established a guiding philosophy for future State policy. The following excerpt from the preamble expresses the overriding philosophy:

Too often, quality of life [in other words, “a good life”] is not impaired by disability but by societal attitudes toward disability.... We as a society must work to eliminate negative values and attitudes that continue to be the most formidable barriers experienced by people with disabilities.... The goal of social policy and services should be the positive growth, development, and dignity of individuals. (*State Plan on Disabilities*, 1990, pp. 12-13)

The principles on the following page are adapted from the 1990 policy framework that was developed by persons with disabilities at the time. Some modifications have been made to reflect updated language, and the principles could probably be further refined. Still, the core beliefs expressed here are becoming an increasingly prevalent philosophy that will endure. The policy framework from which these principles are drawn, reflected the early expression of a philosophy of independent living that Centers for Independent Living and other advocacy groups have supported since the passage of the Americans with Disabilities Act ten years ago. This independent living philosophy is at the center of the State’s continuing commitment to serve persons with disabilities of all ages (children, young and middle-aged adults, and elders) in the most integrated, least restrictive settings appropriate to their needs, and to offer opportunities for selecting from a variety of appropriate options and settings to the extent the State’s resources allow.

Principles for Supporting Persons with Disabilities

1. **Independent Living**: Independent living involves engaging in all the activities in which other people participate, including living in any of a range of residential options, participating in community activities, using public transportation, working, etc.
2. **Integration**: The integration of people with disabilities into all aspects of community life includes physical, social, political, educational, and economic integration.
3. **Empowerment**: Empowerment includes involving people with disabilities (and their families and legal representatives) in the planning, evaluation, and delivery of services. Empowerment should extend to all people with disabilities to the maximum extent possible.
4. **Participant Control**: People with disabilities should have an active role in planning and choosing the services they receive, regardless of their living situation. This includes being involved with the planning, direction, management, and staffing of the services in which they participate.
5. **Opportunities and Choice**: Policies and services should increase opportunities and choice for maximum involvement in all aspects of society.
6. **Family Support**: Family support services should be flexible, individualized, and designed to meet the diverse needs of families. Family support services should be defined broadly in terms of the needs of the entire family, including children with disabilities, parents (including parents with disabilities), siblings, and other family members.

- 7. Health Promotion and Early Identification:** The goal should be to promote the growth and development of all children, families, and adults. Policies and services should emphasize the prevention of illness, injury, and environmental factors which can lead to disability. These policies should provide for the assessment, identification, and positive response to people with disabilities at the earliest stage of development, as well as at subsequent stages to strengthen capacities.
- 8. Community-Based Services:** Policies and services should be oriented toward a delivery system that is community-based, inclusive, and integrated.
- 9. Accessibility and Adaptability:** Structures, vehicles, and services should be constructed, modified, and planned to assure that they are usable to people with disabilities and offer sustained and long-term support.
- 10. Civil Rights:** Policies and services should ensure equal opportunity and protect the civil rights of people with disabilities of all ages.

(Adapted from the *State Plan on Disabilities*, 1990, pp. 14-20)

The independent living philosophy embedded in these principles forms a basis for planning options that afford people with disabilities equal access to public services, economic opportunity, protection of their civil rights, and an overall emphasis on the promotion of independent living. Since their inception, most State agencies have been involved in long range planning for their populations, and planning for community options has been a critical component of such plans.

1. Collaborative Long-Term Care Planning

In 1998, the Connecticut General Assembly established the Long-Term Care (LTC) Planning Committee, and charged the Committee with the responsibility of developing a long-term care plan for elderly persons. The Committee issued a *Preliminary Plan* in 1999 and the full *Long-Term Care Plan* in 2001. The Plan will be updated every three years. An additional plan, *Home Care for Older Adults: A Plan for Increasing Eligibility Under the Connecticut Home Care Program for Elders*, was issued by the Committee in February 2000.

The LTC Planning Committee includes State agencies, as well as the Chairs and Ranking members of the General Assembly's Committees on Human Services, Public Health, and Aging. A LTC Advisory Council representing elders, people with disabilities, providers, and advocates advises it.

Although the LTC Planning Committee was originally established to plan long-term care services for elders, the Committee determined early on in its work that planning for the needs of older people could not be done in isolation from long-term care planning for the entire population. Therefore, the LTC Planning Committee developed the following broad vision: "To assure Connecticut residents access to a full range of integrated, high-quality, long-term care options that maximize autonomy, choice and dignity."

The legislative mandate for the LTC Planning Committee has been expanded to include all persons in need of long-term care, not just the elderly. Effective July 1, 2001, the LTC Planning Committee is charged to plan for all persons in need of long-term care, including evaluating "issues relative to long-term care in light of the United States Supreme Court decision in *Olmstead*" The Committee's membership has been expanded to reflect its larger mission.

2. State Agency Planning

In 1993, the Departments of Aging, Human Resources (which included the Bureau of Rehabilitation Services), and Income Maintenance were consolidated within a single Department of Social Services (DSS). This large human services agency includes a variety of planning activities which respond to federal and state mandates with regard to persons with disabilities of all ages, including operation of the Medicaid program. DSS partners with a variety of community organizations as

part of its planning activities, notably including the State Independent Living Council (SILC) and the Area Agencies on Aging.

In addition, there are a number of other State agencies engaged in planning alternatives to institutional care for their target populations. These include the Departments of Mental Retardation, Mental Health and Addiction Services, Children and Families, Economic and Community Development, Transportation, and Public Health. All of these planning activities involve stakeholders in the process of developing consensus on plans. The chart on the following page lists the key documents that describe the planning of programs and services to provide alternatives to institutionalization.

There are also a number of other State agencies which play important, though secondary, roles in supporting alternatives to institutionalization, since many programs and services they offer are also critical in the lives of persons with disabilities. These agencies include the Departments of Education, Labor, Veterans Affairs, the Office of Protection and Advocacy, the Connecticut Housing Finance Authority, the Board of Education and Services for the Blind (BESB), and the Commission on the Deaf and Hearing Impaired. Since their core services are not related to long-term support services, their plans have not been addressed here, however, it should be remembered that successful integration into the community involves many kinds of support.

Key Planning Documents Related to
Long-Term Supports and Services for Persons with Disabilities

Title of Document	Agency Responsible	Latest Date
State Plan on Disability Services: The Foundation for the Future	DSS (formerly DHR)	June 1990
Social Services Block Grant Plan	DSS	October 1999
State Plan on Aging	DSS	2000-2001
State Plan for Independent Living	SILC/DSS/BESB	1999-2001
State Plan for Vocational Rehabilitation	DSS	2000-2001
Medicaid State Plan	DSS	Ongoing
DMR's Five Year Plan	DMR	1996-2001
EMPOWER	DMR	May 1999
How to Eliminate the Waiting List	DMR	June 2000
CMHS Block Grant & State Plan	DMHAS	October 01 - September 02
Report of Governor's Blue Ribbon Commission on Mental Health	DMHAS	July 2000
Delivering & Financing Children's Behavioral Health Services in CT	DSS/DCF and others	February 2000
Consolidated Plan for Housing and Community Development	DECD	2000-2005
Institute on Home Health Care: Final Report and Recommendations	CT Assn. For Human Services	Winter 1999
Preliminary Long-Term Care Plan	LTC Planning Committee	January 1999
Home Care for Older Adults: A Plan for Increasing Eligibility Under the CHC Program for Elders	LTC Planning Committee	February 2000
Long-Term Care Plan	LTC Planning Committee	January 2001
CT Community KidCare: A Plan to Reform the Delivery & Financing of Children's Behavioral Health Services	DSS/DCF	January 2001
State Plan for Independent Living	SILC/DSS/BESB	2001-2004

a. Social Services Block Grant Plan: Ongoing activities for persons with disabilities are reflected in the State's *Social Services Block Grant Plan*. This plan documents the State's commitment of Federal Social Services Block Grant funds for a variety of supports and services. The majority of these funds are used for services for persons at risk of institutionalization. These services include case management, home-based services, substance abuse services, special services for persons with developmental or physical disabilities or persons with visual or auditory impairments, independent and transitional living services, protective services, home delivered meals, and counseling. However, this "plan" is designed to be a description of what is covered using these federal funds rather than a strategic planning document. Other planning activities are related to the State's biennial budget process.

b. Elderly Services State Plan: Within DSS, the Elderly Services Division is responsible for State planning related to older persons. This planning includes activities and services that are beyond the scope of a comprehensive plan to promote community integration, but also includes services that are relevant. The following priority areas within the *State Plan on Aging (Federal Fiscal Year 2000-01)* have the greatest relevance to the establishment of a system of community-based alternatives to institutional care.

- Priority Area 1: Health
 - Nutrition
 - Mental Wellness
 - Health Screening
 - Prescription drug assistance
 - Alzheimer's Disease
 - Long-Term Care
- Priority Area 2: Independent Living
 - In-Home & Community-Based Services
 - Housing
 - Transportation
 - Social Integration
- Priority Area 3: Information, Access, and Advocacy
 - Network Development
 - Information, Referral and Advocacy
 - Legal Assistance
 - Conservatorship

c. Independent Living Plan: Within DSS, the Bureau of Rehabilitation Services (BRS), in partnership with the Statewide Independent Living Council and the Board of Education Services for the Blind, oversees the planning of the independent living program in Connecticut. One main component of the program is the five Independent Living (IL) Centers scattered throughout the State. These non-residential resource centers are run by persons with disabilities and provide advocacy services. Each center's Board of Directors plans for their own center. In 2000, IL Centers relocated 35 persons from institutions to the community and assisted 129 persons in avoiding placement in institutions. The *State Plan for Independent Living (2001-2004)* emphasizes a philosophy of empowerment and promotes "the integration and full inclusion of [individuals with significant disabilities] into the mainstream of American society." The three-year plan describes four goals for how resources should be directed. They are quoted here:

- To insure the provision of IL services, specifically core IL services, in all areas of the State;
- To promote the independent living philosophy through the sharing of new techniques, ideas, and innovative approaches;
- To ensure cooperation and collaboration amongst the various agencies and organizations which affect the lives of individuals with disabilities;
- To continue provision of community education, outreach and rehabilitation to elderly blind persons through the Board of Education and Services for the Blind.

d. Vocational Rehabilitation Plan: BRS also oversees the State planning activities for vocational rehabilitation. *The State Plan for Vocational Rehabilitation* serves persons with significant disabilities whose goal is employment, thus enabling them to remain active members of their communities. Like the plan for independent living services, the plan for vocational rehabilitation emphasizes empowerment and focuses on vocational opportunities as a vehicle for empowering persons with disabilities. The plan describes five goals along with more specific activities and progress updates. They are quoted here:

- Enhance employment outcomes for people with the most significant disabilities, especially minorities and other traditionally underserved populations;

- Serve employers as customers, resulting in increased employment opportunities for individuals with disabilities;
- Foster program development with particular attention to consumer empowerment and choice;
- Provide opportunities for leadership development and succession planning;
- Market the programs and services of the Vocational Rehabilitation program to engage more individuals with disabilities and to increase employment opportunities.

e. Medicaid State Plan: The DSS Program Division and the DSS Medical Care Administration (MCA) Division oversee the *Medicaid State Plan*. The Program Division is responsible for eligibility policy and procedures that describe who is eligible for Connecticut's Medicaid program. The MCA Division is responsible for policies and procedures that describe what is covered under Connecticut's Medicaid program. The *Medicaid State Plan* is designed to be a description of who and what is covered under Medicaid rather than a plan for the future. As such, it is not the vehicle for true planning for change. The actual planning for the future of Connecticut's Medicaid program happens through collaboration in the planning processes described above, collaboration with other State agencies, and the planning related to the State's biennial budget. Because of the federal matching funds available under Medicaid, expansion of Medicaid services to special needs populations is a key element in the discussion of all strategic planning for community-based services within the State.

f. Planning of Mental Retardation Services: The Department of Mental Retardation (DMR) produces a five-year plan. The 1996-2001 plan is entitled *Connecticut Communities Include. . . .* This document reaffirms DMR's commitment to provide services and supports needed by the citizens of Connecticut with mental retardation. In May 2000, the Department released a report, *How to Eliminate the Waiting List: Study and Recommendations*, that proposes a plan for DMR to meet the needs of people waiting for services and supports.

In May 1999, DMR issued a planning document entitled *Expanding Meaningful Placement Options With Equity and Respect (EMPOWER)*. The report documents

the DMR's commitment to enhancing choices for residents of the Southbury Training School, the only remaining State-run training school for persons with mental retardation. The following elements are identified as the "cornerstones" of the DMR commitment:

- Informing and responding to resident/guardian/family/advocate/ Interdisciplinary Team interest in residential placement, support and service alternatives;
- Continuous assessment of residential placement, support and service preferences and choices;
- Responding to known demand for residential placement, support and service alternatives within the normal budget process and through available resources;
- Establishment and maintenance of a funded "community options reserve" to respond to changing demand for residential placement, support and service alternatives throughout the fiscal year; and
- Establishment of [Southbury Training School] as part of the community service system, directly linked to the DMR Northwest Region.
(*EMPOWER*, May 1999, pp. 1-2)¹⁶

In addition, DMR engages in ongoing planning activities as part of the biennial budget. In the biennium ending June 2001, the Department has been appropriated \$16.3 million for new residential services for people on the waiting list, \$25.3 million for residential and day services for other specific populations, and \$5 million for Southbury residents who wish to move to the community. This, together with the focus on self-determination, has enabled DMR to dramatically increase choices and opportunities for persons with mental retardation.

g. Planning of Mental Health Services--Connecticut Behavioral Health Partnership: DSS, the Department of Children and Families (DCF) and the Department of Mental Health and Addiction Services (DMHAS) have formed the Connecticut Behavioral Health Partnership to plan and implement an integrated

¹⁶ The placement process for Southbury Training School residents is an issue in *Messier v. Southbury Training School*, currently in U.S. District Court.

public behavioral health service system for adults, children, and families. The Behavioral Health Partnership (“Partnership”) has three goals:

- Administrative integration
- Service delivery redesign
- Revenue maximization.

Administrative Integration

There are a number of reasons that the Departments are working toward the development of an integrated infrastructure for the administration of behavioral health. Under the proposed model, administrative integration will enable the State to integrate funding streams in order to support comprehensive and longitudinal care planning. The integration of funding streams will make it easier for providers and clients to develop community-based individualized care plans that rely on multiple funding sources (e.g., Title IX, State general fund, Title IV-E). This in turn will accomplish several important State objectives:

- Reduce unnecessary institutional care;
- Improve efficiency and reduce administrative costs to the State;
- Improve administrative performance in key areas such as claims processing, utilization management, and data management; and
- Improve our ability to design and manage performance-based clinical service contracts.

It will also enable the State to introduce utilization management to areas of service delivery that have thus far been under-managed (e.g., residential care). It will eliminate the incentive to cost-shift to alternative and often more expensive service types and payers such as currently exist between the HUSKY managed care organizations and the DCF residential service system. Finally and not inconsequentially, it will reduce the administrative burden and cost to providers.

Service Delivery Redesign

DCF, DMHAS, and DSS are redesigning the behavioral health service delivery system in accordance with the needs of their respective programs. Connecticut Community KidCare is the DCF led reform initiative designed to tailor the system to the needs of children with serious emotional disturbance and their families. The Recovery Healthcare Plan for Adults is the DMHAS led initiative designed to address the needs of adults with serious psychiatric and addiction disorders. DSS is participating in and supporting both of these service redesign initiatives. The child and adult systems are being redesigned along common principles:

- Children/families/consumers as partners
- Community-based
- Cost-effective
- Culturally competent
- Evidence-based
- Recovery focused
- Flexibly planned
- Informed choice about treatment options
- Prevention and early intervention
- Care coordinated across multiple providers
- Accountability to consumers, providers, and taxpayers

It is anticipated that these reforms will improve the ability of child and adult clients to remain in their homes and communities, to avoid unnecessary hospital admissions and extended institutional stays, and to improve client satisfaction and outcomes with respect to independent functioning and quality of life.

Revenue Maximization

The service delivery reforms described above will depend on the enhancement of community-services that provide an alternative to institutional care. DCF is currently funding a range of community services (e.g., home-based psychiatric, mobile crisis, case management, respite) and is introducing nearly \$14 million dollars worth of new services over the next two years, most of which would be eligible for federal reimbursement under Medicaid if they were added to the Medicaid State plan under the rehabilitation option. DMHAS is also funding a range of community-based services such as assertive community treatment teams, mobile crisis teams, residential rehabilitation and psychosocial rehabilitation,

which would also be reimbursable if DSS implemented an adult rehabilitation option. The Departments are currently conducting an actuarial analysis to investigate the costs and benefits of implementing child and adult rehabilitation options. Similarly, although currently a Medicaid reimbursable service, it is anticipated that the revenue generated under the adult Targeted Case Management (TCM) option may be greatly enhanced through improved management of this service.

Implementation of these reforms is likely to occur over a 3-5 year timeframe. Taken together, these changes will dramatically improve the quality of behavioral health services that DSS provides to beneficiaries of Medicaid, SCHIP, and other publicly funded programs providing behavioral health services.

h. Planning for Children's Services: Under the Behavioral Health Partnership, DCF, and DSS are in the process of implementing Connecticut Community KidCare, Connecticut's developing System of Behavioral Health Care for children and their families. KidCare is grounded in a model in which service planning and delivery is driven by the needs and preferences of the child and family. Emphasis will be on early intervention through the opportunity to access an array of culturally competent, quality services. Services are intended to be flexible and responsive and may be delivered in the home or in the community. Community and home-based clinical services will be enhanced by non-traditional, development enhancing support opportunities. Inpatient and residential services will complement the community services when more intensive services are indicated. In order to provide immediate access to behavioral health specialists and to assist in behavioral health emergencies, mobile crisis services are being developed in 12 sites assuring statewide availability.

For children with complex behavioral health needs and their families, care coordinators will partner with families and local service agencies to create a comprehensive, coordinated, individualized service plan. Local Community Collaboratives will guide system development and form Child Specific Teams of appropriate membership to work with each family. This plan will assist the child and family in resolving school, home, community and relationship problems intended to result in stronger families and healthier children.

Goals of System Change. KidCare will result in significant change in several areas. Each area is important in the development of a responsive and well-designed System of Care for Children and Families.

- *Family Involvement:* Families will play an instrumental role in ensuring that every aspect of the System is accountable and responsive to the behavioral health needs of children and their families. DCF is supporting the development of a Family Support Organization to assure that the children and families have a voice, access and ownership in the development and implementation of their service plans. Families are also important partners in all system and service design activities.
- *Improved Coordination of Care:* Care Coordination is the framework for assisting families and their children in accessing the services that best meet their needs. When multiple services are included in the service plan, the care coordinator assists the family in using and accessing all the services and facilitates communication between service providers and the family when needed. Parents and providers have been active participants in the defining of the care coordination service. Parents were included in the selection of the providers of care coordination services.
- *Enhanced Community-based services and treatment alternatives:* A wider array of culturally responsive, quality services is one cornerstone of the service system development. A full complement of behavioral health treatment services including outpatient treatment, intensive outpatient treatment, extended day treatment, partial hospitalization, behavior management services, behavioral consultation, home-based services, residential treatment, professional parent homes, therapeutic foster care and inpatient psychiatric hospitalization, will combine with support services such as respite and flexible funds. When clinical and support services are combined with care coordination and mobile crisis services, a comprehensive system of care exists. Parents and providers are active participants in the design of the services and the service system.
- *Evaluation:* DCF has contracted with the Child Health and Development Institute of Connecticut (CHDI) to assist in the design and development of an evaluation to provide information, analysis and feedback about the services and the operation of the service system. There is an independent evaluation team, Health Services Research Institute (HSRI) that will work closely with the CHDI and DCF. The evaluation is intended to foster accountability, cost consciousness, and responsiveness to those in need of and using the services. Parents and providers play an essential role in the design of the evaluation and in the evaluation process.

- *Quality Management:* DCF and DSS will conduct quality management activities at multiple levels within the KidCare program. DCF and DSS are developing performance measures against which the State and the providers can assess the effectiveness of the behavioral health care system. Performance measures will be identified in the areas of clinical process and outcomes, finance and administration. Quality management will include a sentinel event review with a focus on system wide quality improvement. Parents are assisting in the development of the performance measures and focus of quality management activities.
- *Training and Staff Development:* Changing practice will require ongoing mentoring, supervision, and support in addition to the acquisition of new skills. DCF has contracted with the Child Health and Development Institute of Connecticut, Inc. (CHDI) to design a training plan and to develop a curriculum. CHDI partnered with the Human Service Collaborative of Washington, DC to assist in this effort. The purpose of the initial training will be to implement a competency-based curriculum to improve the knowledge, skills and attitudes of front-line, supervisory, and management staff from DCF and staff in the service agencies with which DCF contracts. Parents, providers, DCF staff and family advocates formed a core team to work with the Human Service Collaborative in the design and implementation of the training.

Current Initiatives. In order to provide a more comprehensive and accessible base of community services, DCF is currently engaged in the following initiatives:

- *Emergency Mobile Crisis Services:* DCF is procuring statewide mobile emergency crisis services. The service model ensures that teams of professionals are available to conduct emergency mental health assessments, substance abuse screenings, and services for children in their homes, emergency rooms, schools and community settings. A specialized mental health care coordinator will be assigned to provide support and assistance to the child and family as community and other resources are identified as needed for on-going service and treatment.
- *Care Coordination Enhancement:* DCF is procuring additional care coordination services across the State to better meet the need for these services. Care Coordinators partner with families and are responsible for convening child specific service teams, they insure the development of an individualized service plan for the child and/or family, and to collaborate with the family, child, providers and DCF (when warranted) to monitor the effectiveness of the services.

- *Community Service Expansion:* DCF is expanding service capacity in key areas of community service: extended day treatment services, home-based behavioral health services, multi-systemic therapy, and behavior management services. These services are designed to be responsive to children and families that seek services through the crisis programs (or other community venues), but are also an important community system building block that will facilitate diversions from and shorter stays in residential treatment services and other more intensive and restrictive treatment options.
- *Crisis Stabilization Beds:* The addition of short, stabilization focused options for children in crisis are being developed in each of the five regions. These services, in combination with mobile crisis interventions and expanded in-home services, are intended to assist children and families when a crisis situation might otherwise result in an unnecessary hospitalization, shelter or other temporary service. Children and families can often re-stabilize, engage with services and keep much of the daily routine of life (school, friends, home-life) intact while obtaining treatment and support.

The Child Implementation Team of the Behavioral Health Partnership is working to ensure that development of all components of the service delivery system for children are in close alignment with the development of the administrative and financial infrastructure.

i. Planning for Housing: Connecticut's *2000-2005 Consolidated Plan for Housing and Community Development* (ConPlan) brings together all the planning and application materials for the housing and community development funds that are allocated on an annual basis by the United States Department of Housing and Urban Development (HUD). This plan integrates economic, physical, environmental, and human development in a coordinated fashion to respond to the holistic needs of Connecticut's communities.

The creation of the ConPlan followed an inclusive and participatory process in which the Department of Economic and Community Development (DECD) convened workgroups. These workgroups involved DECD staff and representatives of other State agencies, the General Assembly, municipalities, the federal government, housing developers, community-based organizations, service providers, tenant associations, and statewide advocacy groups.

The ConPlan is divided into key sections that discuss housing, human service and community development needs, barriers to affordable housing, a citizen participation plan, a housing market analysis, an inventory of state and federal resources that support housing and community development, guiding principles, strategies, priorities and objectives for future coordination and program development, and an Action Plan that describe the allocation of funds for the next federal fiscal year.

Within the ConPlan's *Housing Needs Assessment*, there is a section on "Special Needs Populations," including 'Persons with Disabilities,' 'Persons with Alcohol or Other Drug Addictions' and 'Persons with AIDS/HIV.'

As noted in the ConPlan, people with disabilities are in the midst of an increasingly acute affordable housing crisis. In Connecticut, not one city/town where a person receiving Federal SSI and State Supplemental Income benefits can meet the federal criteria for affordable housing and pay only 30 percent of his or her monthly income for rent. There is a shift from reliance on income streams to rental assistance programs to fill the gap. Both federal and state entitlement/income streams have contributed to this disparity. Neither the federal cost of living adjustment to the SSI benefit program, nor the State Supplemental Income Program, has kept pace with the rising cost of living.

Alcoholism, addiction and mental illness characterize a growing number of people who may require long-term supports. Frequently, people recovering from substance addiction complete treatment programs, yet lack a suitable living environment that will enhance their ability to remain free from their addictions. In addition, a lack of individualized, person-centered planning and follow-up community support services factors into Connecticut's homelessness equation.

Persons living with HIV/AIDS and their families need a wide-range of housing options and an appropriate level of support services in the community to handle more complex life issues. Many of the AIDS housing programs in Connecticut serve individuals but not families. Many supportive housing programs do not accept people with active substance abuse problems, and may require that the person be currently in treatment for chemical dependency. These factors reflect, collectively, a growing need to address the housing needs of all types of households: individuals with dependency issues, single parents, and couples with children.

In summary, these populations are facing extreme barriers to accessing housing. The vast majority of people with disabilities in Connecticut have very little hope of obtaining decent housing in their communities. The past decade has seen an increase in the number of persons who must expend more than 50 percent of their income to secure housing. This has resulted in greater pressure on publicly funded social services to direct scant resources to address this critical housing need. From a system perspective, the flat line income policy has increased pressure on housing subsidy programs. Effective service delivery/treatment is diminished if people lack the income to access housing.

j. Interagency Planning on Home Health Care for Children: While not an official State planning document, the report entitled *Institute on Home Health Care: Final Report and Recommendations*, provides important planning information related to home health care. The report was prepared by the Connecticut Association for Human Services, Inc. in the winter of 1999, and was a result of interagency (public and private sector) planning related to home health services. It was the culmination of meetings held from September through November, 1998, for the purpose of understanding “the challenges... in delivering home-based services to children and young adults” and developing recommendations for improvement. The report includes the following recommendations:

- Enhance the home care delivery system to coordinate benefits and offer increased choice of home care providers;
- Verify the inadequacy and shortage of home care workers;
- Increase the supply of pediatric home health care providers available to families by ensuring that home care agencies are fulfilling obligations through staff capacity enhancements, by increasing pay scales and benefits for men and women, and by making efforts to attain parity in work schedules with providers in other settings;
- Improve information dissemination to families who have children with disabilities;
- Establish standards for pediatric home care and increase training for pediatric home health providers.

APPENDIX H

ADDITIONAL SERVICES PROVIDED BY STATE AGENCIES

The following is a description of additional services provided by some of Connecticut agencies, focusing on services to persons who are aged or have a disability.

1. The Department of Social Services (DSS)

DSS provides a broad range of services to the elderly, people with disabilities, families, and individuals who need assistance in maintaining or achieving their full potential for self-direction, self-reliance and independent living. It administers over 90 programs. By statute, it is the State agency responsible for administering a number of programs under federal legislation, including the Social Security Act, the Rehabilitation Act, the Food Stamp Act, and the Older Americans Act.

Title XIX of the Social Security Act (Medicaid) authorizes federal grants to States for medical assistance to low-income persons who are age 65 or over, blind, disabled, or members of families with dependent children or qualified pregnant women or children. Medicaid is jointly financed by the federal and state governments and administered by the states. DSS is the single State agency for the administration of the Connecticut Medicaid Program. The DSS Program Division and the Division of Medical Care Administration jointly oversee Connecticut's Medicaid State Plan. The Program Division is responsible for eligibility policy and the Division of Medical Care Administration is responsible for medical services covered under the Connecticut Medicaid State Plan.

a. The Division of Medical Care Administration (MCA): MCA is responsible for overseeing the administration and operations of Medicaid and related health care programs. Medicaid provides remedial, preventive, and long-term medical care for income-eligible children and their parents and income-eligible pregnant women (under HUSKY A, a managed care program) and income-eligible adults with disabilities and income-eligible elders (under fee-for-service). Benefits include, among other services, physician services; clinic services; Early and Periodic Screening, Diagnostic, and Treatment services (EPSDT); urgent and emergency care; radiology; physical and osteopathic manipulation therapy; dental, vision, and hearing care; medical and surgical supplies, orthotic and prosthetic

devices, durable medical equipment, pharmacy, laboratory testing, outpatient and inpatient hospital services, nursing facility care, care in an Intermediate Care Facility-Mental Retardation (ICF-MR), home health services, medical transportation, and mental health and addiction services.

The MCA Division also oversees the State's Children's Health Insurance Program (SCHIP), known in Connecticut as HUSKY B. HUSKY B is a managed care program open to uninsured children in Connecticut whose family income is over 185% of the federal poverty level. There is a comprehensive benefit package, which includes, among other services, preventive care; prescriptions; lab and x-ray; dental, vision, and hearing care; prosthetics; home health; and mental health and addiction services. Within HUSKY B there are two supplemental programs for children with intensive physical or mental health needs, entitled HUSKY Plus Physical and HUSKY Plus Behavioral. The HUSKY Plus Physical program is administered in concert with the Department of Public Health's Children with Special Health Care Needs program. The Departments work collaboratively in overseeing the two programs. The diagnostic eligibility criteria, the services benefit package, and the provider network are substantially the same in both programs.

In addition, the MCA Division oversees the medical benefits for persons who qualify for General Assistance (GA) and the State Administered General Assistance (SAGA), which cover almost all services that are covered under the Connecticut Medicaid program with the exception of long-term care and non-emergency medical transportation. The Division also administers the Connecticut Pharmaceutical Assistance Contract to the Elderly and the Disabled program (ConnPACE), which assists eligible individuals in meeting the cost of prescription drugs and the Connecticut AIDS Drug Assistance program (CADAP), which pays for drugs determined by the U.S. Food and Drug Administration to prolong the life of people with AIDS, or HIV infection.

Medicaid Waivers

The federal government allows states some flexibility in implementing Medicaid. This usually requires a waiver application when the State wishes to expand eligibility or vary the benefit package and/or delivery system. Medicaid waiver programs can offer home and community-based services to individuals in specific target populations who would otherwise need to receive services in institutional settings. Certain limits on regular Medicaid coverage (such as comparability and statewideness) are "waived" making it possible to offer traditional Medicaid services and a broader range of support services to individuals who might

otherwise not qualify for Medicaid. Thus, individuals who qualify for waivers also qualify for full Medicaid benefits, and often utilize home health services (nursing, home health aide, therapy services) along with the support services offered under the waiver. The MCA Division oversees the Elder Waiver (the Connecticut Home Care Program for Elders) and the Katie Beckett Model Waiver and works with the Department of Mental Retardation on the DMR Waiver. The Division of Social Work and Prevention Services administers the Personal Care Assistance (PCA) Waiver and the Acquired Brain Injury (ABI) Waiver. These waivers are discussed in more detail in Section II, Existing Programs.

b. The Division of Adult Services: Adult Services is responsible for eligibility policy and procedures for the State Supplement program, the adult Medicaid coverage groups including all the waivers discussed above, the Medicaid for the Employed Disabled program and State Administered General Assistance (SAGA). Adult Services also provides technical support to the 15 field offices in the State that provide direct services to eligible individuals.

The State Supplement for the Aged, Blind, and Disabled provides monthly benefits to low income individuals for basic living expenses. The adult Medicaid coverage groups provide medical assistance to Connecticut residents over the age of 18. The Medicaid for the Employed Disabled program allows persons with disabilities to engage in employment without risking eligibility for needed medical services through the Medicaid program. It is discussed more fully in Section II, Existing Programs.

The Adult Division also provides policy, procedural and technical support for the administration of the Medicare Savings Programs (QMB, SLMB, ALMB-I, and ALMB-II). These programs are special Medicaid coverage groups that help eligible individuals meet the cost of Medicare premiums, co-insurance and deductibles. Benefits vary for each group. Eligibility for one of the groups is determined by the individual's countable income and for some groups, assets

SAGA has both cash and medical components. The medical component provides medical assistance for some individuals and families who do not qualify for, or who are awaiting an eligibility determination for, other state or federal programs.

The Adult Division also directly administers the Connecticut Insurance Assistance Program for AIDS Patients (CIAPAP) and the Connecticut Organ Transplant Program (ConnTrans). CIAPAP assists individuals who are unable to continue working and risk losing group medical insurance because of AIDS or an AIDS-

related disease. Medical insurance premiums are paid on behalf of eligible individuals who qualify for and who elect to continue their group medical insurance coverage for the time period allowed under state or federal law. ConnTrans helps Connecticut residents pay for medical and ancillary costs associated with organ transplants. The program is funded through contributions primarily from individuals who donate part of their income tax refund to the fund.

c. The Division of Social Work and Prevention Services (SW): SW provides services to promote physical, social and economic well-being to persons with disabilities under the age of 65 years. These services promote independent living and provide alternatives to institutionalization for adults with disabilities and families of children with disabilities.

Besides the PCA Waiver and ABI Waiver, discussed in Section II, Existing Programs, the SW Division administers the Adult Protective Services program. Social work services are provided in cases where vulnerable adults with disabilities between the ages of 18 and 59 are alleged to be abused, neglected or exploited. A small amount of funding is also available to pay for services that are not otherwise available under other DSS programs.

The SW Division works closely with an advisory council, the Connecticut Council for Persons with Disabilities, comprised primarily of people with disabilities. The Council makes recommendations to improve the planning, development and administration of programs.

d. The Division of Elderly Services: Elderly Services provides services which are necessary to assure the health, safety and welfare of elderly persons, as well as services to assist elderly or aging persons to enjoy wholesome and meaningful living. Within Elderly Services is the Long Term Care Ombudsman Program. It's mission is to protect the health, safety, welfare and right of long term care residents by, among other things, investigating complaints of residents, providing community education, and promoting and supporting Resident and Family Councils.

In addition, Elderly Services provides Federal Older American Act funds and State funds to five Area Agencies on Aging (AAA) within the State. The AAAs then allocate these funds to elderly service providers in the following four categories: Social Services, Nutritional Services, In-Home Services for Frail Elderly, and Preventive Health Services. Through the AAAs, the Division maintains the 1-800-CHOICES number, which provides information to consumers on health insurance,

counseling, and general information on services available to the elderly. The ES Division also administers the National Family Caregiver Support Program, which provides information and assistance to caregivers of all ages.

e. The Bureau of Rehabilitation Services (BRS): BRS provides services to enable people with disabilities to prepare for, find, and keep jobs in their communities. Throughout the vocational rehabilitation process, the emphasis is on employment, through partnership and collaboration. The needs and goals of the consumer are balanced with the knowledge, resources and skills of the vocational rehabilitation counselor. Services are provided directly by the Vocational Rehabilitation program and also may be purchased from other agencies, service providers and community resources. In some cases, consumers may contribute financially toward parts of their employment plan.

In addition to its main program of Vocational Rehabilitation (VR), the Bureau offers an array of services that run the gamut from promoting independent living options to enhancing supports and opportunities in the work world.

- **Employment Opportunities Program (EOP):** Since 1991, the Bureau has been managing the EOP, which targets persons with significant disabilities who need ongoing support services in order to work in integrated, competitive settings in their communities. The EOP assists persons who, after completing intensive VR services, need customized support services to meet their particular employment needs, but who are not eligible for long-term funding supports from other public agencies.
- **Connect to Work Center:** The Bureau has been awarded two federal grants to support the employment of persons with disabilities in the competitive labor force. This has resulted in the establishment of the Connect to Work Center, whose goals include:
 - Establishing a statewide network of benefits counselors, available to individuals with disabilities, families, employers, service providers and advocacy groups.
 - Providing a single access point for information and assistance around benefits and services, connecting the key components of employment, health care, personal assistance and benefits counseling.

- Providing training, public education and outreach around benefits and services offered within the State of Connecticut (with a particular emphasis on the Medicaid for the Employed Disabled Program).
 - Conducting policy review and policy development to enhance opportunities for individuals with disabilities to enter the labor force.
- **Connecticut Tech Act Project:** BRS administers this program, which is designed to make it easier for citizens with disabilities to get the technology they need for greater independence at work, school, and in the community. The project does this by creating programs to fund technology, removing system barriers to the acquisition of technology, creating awareness of the role of technology as a tool for independence, and working in partnerships with other agencies and organizations. The project covers all ages and crosses all disabilities, and is funded by a grant from the National Institute on Disability Rehabilitation Research (NIDRR). The project's low-interest loan program provides loans for those who qualify to purchase assistive technology devices or modify vehicles and homes.
 - **Independent Living:** The Bureau provides comprehensive independent services through contracts with Connecticut's five Centers for Independent Living. This statewide network of community-based, consumer-controlled organizations promote independence for people with disabilities through the provision of the four core independent living services: peer support; information and referral; individual and systems advocacy; and independent living skills training. One of the main services historically provided by the centers has been to assist people who are institutionalized in the difficult and often complex process of community re-entry.

In addition, the Bureau makes available the consultation services of an Independent Living Counselor who works in partnership with representatives of State agencies, the independent living centers and advocates for persons with disabilities, to problem solve the hierarchy of needs for people with significant disabilities to live as independently as possible in the community. A major initiative continues to be finding ways to restructure services and expand independent living opportunities for persons who are at risk of, or who are, institutionalized.

- **Disability Determination Services (DDS):** The Bureau's DDS unit is responsible for deciding eligibility for the Social Security Disability Insurance

(SSDI) and Supplemental Security Insurance (SSI) programs. These programs provide case benefits to individuals with disabilities who are currently unable to engage in gainful employment.

2. The Department of Mental Retardation (DMR)

a. Case Management: A continuum of supportive activities, carried out by an individual case manager, that are available to assist and enable an eligible person to gain access to needed medical, social, educational or other services. Each individual is assigned a case manager who focuses on his or her situation. (DMR has more than 14,000 persons eligible to receive case management services.)

b. Residential Habilitation: Assistance with acquisition, retention or improvement of skills related to activities of daily living, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, and the social and adaptive skills necessary to enable the individual to reside in a non-institutional setting.

DMR funds approximately 3,400 people in Community Living Arrangements (Group Homes), 1,400 in Supported Living, 500 in Community Training Homes, and less than 100 in Residential Schools. This totals approximately 5,400 people. In addition, approximately 500 people who are clients of the Department live in other residential settings not funded by the Department.

c. Individualized Supports: Individually tailored supports to assist persons with mental retardation to live in their own home, family home or other home in the community. These supports may be delivered in the home or community and may include personal assistance, adaptive skill development, adult educational supports, transportation, social and leisure skill development, respite, parent training, environmental modifications, clinical and medical supports and adaptive equipment and supplies not covered by insurance, support planning, coordination and administration. The person or his or her family has a person-centered supports agreement that includes an individual plan describing the supports and services to be obtained or provided and anticipated outcomes to be achieved. The person or his or her family has an individualized budget with portable funds and the person or his or her designee controls the distribution of the funds and resources. Individualized supports may include self-directed supports or enhanced family supports. (There are approximately 400 people utilizing individualized supports.)

d. Campus Settings: DMR operates ICF-MR residences in campus settings for individuals with mental retardation. (DMR serves approximately 900 people in a variety of campus settings throughout the State.)

e. Day Habilitation: Assistance with acquisition, retention, or improvement in self-help, socialization and adaptive skills which takes place in a non-residential setting, separate from the home or facility in which the recipient resides. Services shall normally be furnished 4 or more hours per day on a regularly scheduled basis, for 1 or more days per week, unless provided as an adjunct to other day activities included in the recipient's plan of care. Work is not the focus of this program but may occur up to 10 percent of a person's program time. (DMR serves over 3,000 people in the Day Support Option model.)

f. Prevocational Services: Services not available under a program funded under Section 110 of the Rehabilitation Act of 1973 or Section 602 (16) and (17) of the Education of the Handicapped Act. Services aimed at preparing an individual for paid or unpaid employment, but which are not job task oriented includes teaching such concepts as compliance, attending, task completion, problem solving and safety. When compensated, clients are paid at less than 50 percent of the minimum wage. (DMR serves approximately 1,100 people in Sheltered Employment.)

g. Supported Employment: Services, which consist of paid employment for persons for whom competitive employment at or above the minimum wage is unlikely, and who, because of their disabilities, need intensive ongoing support to perform in a work setting. Supported employment is conducted in a variety of settings, particularly work sites in which persons without disabilities are employed. Supported employment includes activities needed to sustain paid work by waiver clients, including supervision and training. (DMR serves approximately 4,000 people in Individual Supported Employment and Group Supported Employment.)

h. Respite Care: Services given to individuals unable to care for themselves; provided on a short-term basis because of the absence or need for relief of those persons normally providing the care. (DMR provides respite to over 3,000 people.)

i. Family Support: The Family Support Grant program offers cash grants to families that may be used to defray extraordinary expenses incurred as a result of caring for children with severe disabilities. (DMR funds approximately 800 people.)

j. The Birth to Three System: Birth to Three is a state and federally funded entitlement program for families whose children are under the age of three and have significant developmental disabilities or delays. The mission of the system is to strengthen the capacity of families to meet the developmental and health-related needs of their infants and toddlers who have delays or disabilities. The system will ensure that all families have equal access to a coordinated program of comprehensive services and supports that are family centered, occur in natural settings, foster collaborative partnerships, and recognize current best practices in early intervention. (Over 6,500 infants and toddlers are served annually.)

3. Department of Mental Health and Addiction Services (DMHAS)

For persons diagnosed with mental illness, the following are descriptions of community-based long-term support services. The number of identified clients served represents unduplicated clients within that level of care during FY 2001.

a. Case Management: Case management refers to the provision of services that meet the multiple needs of persons with severe and persistent mental illness. Case management services are provided in a variety of settings and include support services which assist the person (client) in gaining access to needed treatment as well as medical, social, educational, vocational, housing, and other services essential to meeting basic human needs. Case management is a client-driven process aimed at facilitating recovery by involving and sustaining the client in realistic and appropriate activities developed and agreed upon by both the client and the case manager. The client's level of functioning and the severity and duration of his/her mental illness determines the intensity and length of time case management services are provided to him or her. (DMHAS served 10,396 clients.)

b. Outpatient Clinical Services: Outpatient clinical services include evaluation, treatment and recovery services provided by mental health professionals. Clinicians, nurses and psychiatrists see clients in regularly scheduled sessions for individual, group and/or family therapy, and psychiatric evaluation and medication management. (DMHAS served 20,252 clients.)

c. Vocational Services: Vocational services are directed at helping clients prepare for, obtain and maintain employment. Employment services may include assistance with competitive employment, supported work placement, placement assistance, on-site job coaching, employment counseling and supervision, job

development and employer consultation services, functional job training, and assisting with, as well as obtaining, job interviews. (DMHAS served 2,582 clients.)

d. Day Treatment/Social Rehabilitation: Day treatment/social rehabilitation offers clients long-term, supportive mental health programming in a therapeutic environment where improving daily living, interpersonal and life management skills are the focus. Additionally, prevocational skill building is addressed through temporary, transitional or volunteer work assignments. As appropriate, a range of clinical activities such as diagnosis, individual or group therapy, rehabilitative services, and access to psychiatric, medical, and laboratory services are provided. (DMHAS served 5,477 clients.)

e. Supported Residential Services: Supported residential services are directed towards enhancing the client's ability to live independently in the community. (DMHAS served 2,766 clients.) Services are provided at the following residential levels:

- **Group Home:** Multiple clients are served in a congregate setting that is continuously staffed.
- **Supervised Apartments:** Clients reside in apartments in the community where staff supervision is available 24-hours a day within the apartment setting. Services may include assistance in all areas of daily living, community integration, education assistance and counseling, client management of personal finances and budgeting, referrals to all necessary services, meal preparation, improving communication skills, and use of leisure time.
- **Supported Apartments:** Clients reside in apartments in the community where staff support may be available 24-hours a day. Services are similar to those provided under supervised apartments.
- **Transitional Residential:** This is a short-term program for clients transitioning from more to less restrictive settings. Residential support is provided until more permanent housing is secured. Services will include case management functions and may also include housing resource coordination to aid the client in finding, obtaining, and keeping safe, affordable housing.

- **Respite:** This service provides intensive residential care to treat a rapidly deteriorating mental health condition. The goal is to reduce the risk of harm to self or others, stabilize psychiatric symptoms or behavioral and situational problems (including substance abuse) and avert the need for acute hospitalization. Respite beds may also be used for transitional care for clients on leave from, or who have been discharged or transferred from, other inpatient or residential facilities.

f. Emergency/Crisis Services: Emergency/crises services are available 24-hours a day and are concentrated interventions to treat a rapidly deteriorating mental health condition. The goal is to reduce harm to self or others, stabilize psychiatric symptoms or behavioral or situational problems (including substance abuse) and avert the need for acute hospitalization. A crisis program is mobile providing accessible, rapid response services to individuals and families experiencing acute psychiatric crisis. Program activities include assessment and evaluation, diagnosis, hospital prescreening, medication evaluation, and referral for continuing care, if needed. When appropriate, brief clinical treatment may be provided to support the client until he or she is transferred to the most appropriate level of care or is discharged. (DMHAS served 4,429 clients.)

4. Department of Children and Families (DCF)

a. Care Coordination: Through the local Systems of Care, children with serious emotional disturbance (SED) and their families are eligible for Care Coordination. Care coordinators provide families with linkage to community-based services, coordination of services and advocacy. The purpose of care coordination through the Systems of Care is to facilitate the return of children to their community from residential placement and prevent the removal of children from their home and community due to mental health needs.

b. Outpatient Counseling Services: The Department of Children and Families partially funds twenty-seven (27) Child Guidance Clinics. These community-based mental health agencies are designed to effectively decrease the prevalence and incidence of mental illness and emotional disturbance in children and youth, and promote mental health in children. Child Guidance Clinics provide diagnosis, evaluation, treatment and specialized treatment for children and their families.

c. Extended Day Treatment Programs: Extended Day Treatment is a program for children who have returned from out-of-community home care or are at risk of placement due to mental health issues or emotional disturbance. Children participating in this service receive a coordinated array of comprehensive therapeutic services before and/or after school with a focus on treatment and psychosocial rehabilitation.

d. Respite Care: Temporary care in the home or community is available to children and adolescents with emotional and/or behavioral health special needs. Respite care provides relief to the child/adolescent's caregivers. Such care will assist these children and youth in being maintained in their homes and communities.

e. Emergency Mobile Psychiatric Services (EMPS): Emergency Mobile Psychiatric Services provide community-based crisis intervention services designed to prevent avoidable residential placement. The provided services include emergency assessment, short-term crisis stabilization and follow-up referral. This service is provided in-home or other locations and is available 24-hours per day, 7 days per week.

f. Family Advocacy: Families receiving the services of their local Systems of Care are eligible for Family Advocacy. The role of the Family Advocate is to assist, support, inform and provide direct advocacy to families and children with serious emotional disturbance. In addition, Family Advocates empower families by promoting parental inclusion in all levels of decision-making and treatment planning.

g. Mentoring: DCF committed or involved youth, ages 15-20, who are in need of support and skill development and who are preparing for independent living in the community may be matched with an adult who serves as a positive role model.

h. Intensive Family Preservation: Intensive Family Preservation is an in-home service offered to strengthen families and reduce the risk of further abuse and neglect for families with children at imminent risk of out-of-home placement. A range of clinical and concrete services are available, such as: parenting; education; advocacy; counseling; crisis intervention; developing linkages with natural helpers and community resources; and training about child development, life management, problem solving, home maintenance, etc.

i. Parent Aide: Families where a child is at risk for maltreatment or placement disruption may receive this service. Parent Aide programs are home-based, paraprofessional services that include parent education and support, role modeling, household management, referrals and service coordination.

j. Therapeutic Child Care: Children below age 6 who are at risk for child abuse and neglect are eligible for therapeutic childcare. This service is center-based and includes individualized therapeutic and developmentally appropriate evaluation and treatment to enhance each child's potential. Caregivers are part of the therapeutic intervention through involvement in the treatment planning and are offered parenting training, support and outreach services.

k. Transitional Living Services/Preparation for Adult Living Settings: DCF committed or involved youth, ages 15 to 21, who are currently in a residential placement and are ready to step down to a community setting, but are not ready to live independently in the community may be considered for this program. This service, which includes group home and transitional apartment programs, is part of the Independent Living Program continuum. Qualifying youth are provided with a structured and supervised residential setting that prepares them for transition to community life. A four-pillared approach to care is offered: Health, Mental Health, Education/Vocation and Life Skills.

l. Group Homes: Youth, age 15 or older, who are prepared for a setting less restrictive than residential care or who are unable to reside in foster care are eligible for a group home. DCF Group Homes are licensed community-based facilities with a home-like environment. Youth in these programs receive board and care, counseling, life-skill training and recreation. In addition, educational, vocational and therapeutic services are provided to these youth in the community.

m. Community Housing Assistance Program (CHAP): The final phase of the Independent Living Program continuum is the Community Housing Assistance Program. The semi-supervised, subsidized, scattered site CHAP model is for young people requiring more supervision and community case management than that which is provided through a community agency.

n. Substance Abuse Treatment for Adolescents: DCF funds both outpatient and intensive outpatient substance abuse treatment services for adolescents. Evaluation and treatment services provided by these programs include, but are not limited to: outreach; comprehensive substance abuse assessment or evaluations; drug testing; individual, group and family therapy/counseling; case management;

retention strategies; relapse prevention strategies; and linkages to recovery support services.

o. Psychiatric Hospitalization: The Department operates Riverview Hospital for Children and Youth, the only State operated psychiatric hospital for children. Admission is open to all citizens of Connecticut who require this level of acute care.

p. Residential Treatment: DCF also provides residential treatment in two sites, High Meadows in Hamden and Connecticut's Children's Place in Windsor Locks. The purpose of these facilities is to provide evaluations and treatment necessary to prepare youngsters for treatment in less restrictive settings.

5. Department of Economic and Community Development (DECD)

Housing Services for Persons with Disabilities

a. Section 29-273 Connecticut General Statutes (CGS)

- "Any complex or building...containing in the aggregate 25 or more dwelling units shall provide at least one dwelling unit accessible to and usable by persons with disabilities for every 25 such units or fraction thereof."
- Administered by Public Safety.

b. Section 29-271 CGS

- Any state-assisted rental housing constructed or substantially rehabilitated on or after 1/1/76, and which contains 10 or more housing units shall have at least 10 percent of the units and all common areas and facilities designed for the physically disabled, as defined in Section 1-1f(b) of CGS.
- Section 1-1f(b) reads - "*An individual is physically disabled if he has any chronic physical handicap, infirmity or impairment, whether congenital or resulting from bodily injury, organic processes or changes or from illness, including, but not limited to, epilepsy, deafness or hearing*

impairment or reliance on a wheelchair or other remedial appliance or device."

- Since 1976, DECD (formerly DOH) has constructed or substantially rehabilitated more than 300 units designed for the physically disabled.

c. Elderly Housing - 7,426 Units

- Section 8-113a.(m) defines "elderly persons" as persons sixty-two years of age and over or persons who have been certified by the Social Security Board as being totally disabled under the Federal Social Security Act or certified by any other federal board or agency as being totally disabled.

d. Congregate Housing - 970 Units

- Alternative to institutionalization for persons 62 years or older and frail.

e. Assisted Living Demonstration – 300 Units

- Grants provided for up to five contractors to develop assisted living pilot projects for up to 300 units of assisted living for persons age 65 and older who qualify for the Connecticut Home Care Program for Elders.

f. Supportive Housing - Homeless/Disabled - 281 Units

- Cedar Hill, New Haven - 25 units
- Crescent Building, Bridgeport - 38 units
- Fairfield Avenue, Bridgeport - 34 units
- MSP Apartments, Hartford - 30 units
- Hudson View, Hartford - 28 units
- Brick Row, Windham - 30 units
- Liberty Commons, Middletown - 40 units
- Ludlow Street - 29 units
- Atlantic Street – 27 units

g. Grants for Conversion of Existing Units into Accessible Units for Persons With Disabilities

- Section 8-218(c) - DECD contracts with the Corporation for Independent Living (CIL) for the purposes of making structural or interior or exterior

modifications to any dwelling (ownership or rental) which may be necessary to make such dwelling accessible to and usable by persons having physical or mental disabilities.

h. Accessibility Registry

- DECD has contracted with Coop Initiatives Inc. to develop and implement a housing registry. The registry will be a Web accessible database of available accessible (public and private) units statewide. It is anticipated to be up and running during the year 2002.

i. Resident Services Coordinator Program

- Grants to owners of State financed elderly housing to provide service coordination to elderly and disabled residents.

6. The Department of Public Health (DPH)

DPH oversees Connecticut's Children with Special Health Care Needs Program (CSHCN), a Title 5 program. CSHCN coordinates specialty care services and provides care management and care coordination, advocacy and support, and payment for certain services including, but not limited to, adaptive and specialty equipment, specialty medical services including speech, occupational and physical therapy, specialty pharmacy, and special nutritional formulas. The program utilizes the following medical definition to determine medical eligibility:

“Children who have, or are at elevated risk for, chronic physical, developmental, behavioral, or emotional conditions (biologic or acquired), who also require health and related services (not educational and recreational) of a type and amount not usually required by children of the same age.”

DPH and DSS work collaboratively in overseeing the CSHCN and HUSKY Plus Physical programs. The diagnostic eligibility criteria, the services benefit package, and the provider network are substantially the same in both programs. For the CSHCN program, individuals with cystic fibrosis are not restricted by age limitations.

7. Board of Education and Services for the Blind (BESB)

BESB provides a comprehensive array of services to improve the independent living skills of adults and children who are legally blind or visually impaired. The agency serves approximately 4,000 clients each year. Services include vocational counseling, technology training, teaching to improve activities of daily living, training in use of devices for safe travel, provision of low vision evaluations and aides, and self-advocacy training.

8. Department of Transportation (DOT)

DOT subsidizes fixed-route bus services throughout the State at a cost of \$57 million annually. These fixed-route services provide half-fares to the elderly and people with disabilities (about \$.50 to \$.65 for a one-way trip). All vehicles used are lift-equipped and DOT is currently testing low-floor vehicles due to the enhanced accessibility for all riders.

DOT administers the Federal Section 5310 program, which provides vehicle grants to municipalities and non-profit organizations. The Federal Americans with Disabilities Act of 1990 (ADA) law requires that providers of fixed-route service also provide demand responsive service to pre-qualified individuals who are not able to utilize the fixed-route system. The demand responsive service runs complementary to the fixed-route system, providing service to origins and destinations within 3/4 mile of the fixed-route system during the same days and hours as the fixed-route system. There are no federal dollars available to support this mandate. The State currently spends \$7 million for the ADA services.

APPENDIX I

RECENT DEINSTITUTIONALIZATION EFFORTS in CONNECTICUT

As part of their efforts to shift the balance between institutional and community services, all State agencies in Connecticut have been reducing the size and numbers of their institutions over the years, and reducing the number of persons institutionalized.

1. Department of Mental Retardation (DMR)

Prior to 1985, most services for persons with mental retardation were provided in large state schools or smaller regional centers. At that time, 58 percent of the people who received services accessed them in the community; in 2000, 88 percent are served in the community. (For comparison purposes, this excludes children in the Birth to Three program who are all served in the community, but who were not served by DMR in 1985. If these children are included, the percentage for the year 2000 is 91 percent.)

In the year 2001, one state school was operated by DMR, along with six regional centers certified as intermediate care facilities for the mentally retarded (ICFs-MR). As of December 2001, 631 individuals reside in the Southbury Training School (admissions have been closed since 1986) and 271 persons are served in the regional centers. This compares with over 5,600 individuals presently receiving residential supports in a variety of community settings, including community living arrangements (small group homes), supported living arrangements (private apartments with services brought in) or relatives' homes. Approximately 4,500 non-DMR clients are served in the Birth to Three program. Over 18,500 people receive some type of service from DMR.

2. Department of Mental Health and Addiction Services (DMHAS)

Similarly, the mental health system has changed from three long-term care institutions in 1990, serving an average daily census of 1,512 people, to one long-term care institution (Connecticut Valley Hospital) in 2001, serving approximately 200 people in the general psychiatric division at any given time. (Currently, three acute-care institutions serve approximately 150 people diagnosed with mental

illness at any given time.) In contrast, during FY 2001, a total of 30,491 individuals with mental illness were served by DMHAS in the community.

Please note that these numbers do not include people served in DMHAS substance abuse services or those in the DMHAS Whiting Forensic Division. People receiving inpatient substance abuse services move through the institutions quickly and return to the community with support services on a regular basis.

(Occasionally, support services are not available, but this is not a widespread problem.) Many people in DMHAS' forensic division (who are small in number and who reside at Connecticut Valley Hospital) come under the purview of the Psychiatric Security Review Board (PSRB). The PSRB determines when and under what circumstances the person can be released to the community.

3. Department of Children and Families (DCF)

Despite the increase in the overall numbers of children who come to the attention of DCF, as well as the increasing complexity of their behavioral health needs, the total population of children living in institutional settings has remained relatively stable over the past several years. Several State agencies including DCF and the Department of Social Services (DSS), have made significant efforts toward building and developing local systems of care for children with the most serious and complex problems with an emphasis on comprehensive, coordinated, family-focused and community-based service delivery.

In addition, DCF's Continuum of Care initiative is exploring a flexible funding approach which allows local collaboratives to manage the care of children with serious emotional disturbances within an overall budget cap. These efforts and the plans for further development of local systems of care and flexible funding strategies are outlined in the recent report to the Connecticut General Assembly entitled Delivering and Financing Children's Behavioral Health Services in Connecticut. This statewide collaboration and integrated funding approach will allow for behavioral health service delivery that is more community-based, responsive and accountable.

4. Department of Social Services (DSS)

To some extent, the reduction in large state-operated institutions has been offset by expansions of smaller private facilities, particularly nursing homes. The mandatory availability of Medicaid funding for nursing homes in 1965 stimulated a dramatic growth in the industry across the nation. In some cases, persons with

mental retardation, mental illness, or both diagnoses were transferred from State institutions to these smaller institutional settings.

During the 1980s, Connecticut developed three Medicaid home and community-based services waivers to supplement existing State-funded home care programs. These waivers were the Katie Beckett model waiver, primarily targeting medically fragile children, a waiver for persons with mental retardation, and a waiver for older persons. The Katie Beckett model waiver expanded the size of its target population in the late 1980s and the other two waivers continued to be expanded in the 1990s, both in the number of individuals served and the types of services available. In addition, two new waiver programs were added in the 1990s, targeted to non-elderly adults with physical disabilities and people with acquired brain injury.

Also, in the 1990s, Connecticut's Medicaid program began to offer a service called "targeted case management" to provide assessment and care coordination services to persons with mental retardation or mental illness. The use of traditional home health services (providing nursing, physical and occupational therapy, and home health aides to persons who would otherwise need institutional care) has also grown under Medicaid (and Medicare), although changes following the federal Balanced Budget Act of 1997 have reversed the home health expansion.

The expansion of community options by DSS has helped to provide alternatives to institutional care, and supported the establishment of a moratorium on approval of new nursing home beds in 1991. New nursing facilities approved prior to the moratorium were permitted to proceed to construction and licensure. Therefore, the number of licensed beds continued to increase through 1994. However, since then, the number of beds has stabilized and actually declined by over 800 beds in just the last two years. Since 1997, there has also been a reduction in the average number of nursing facility Medicaid clients by more than 1,200. This shift appears to be directly related to the expansion of home and community-based services waivers under Medicaid.

By using Medicaid funds, Connecticut has been able to greatly expand the range of home and community-based choices available. The State operates five home and community-based services waivers under Medicaid. Federal matching funds available for these Medicaid waiver services have made it possible for the State to expand the total funds available for community-based long-term care services, thus expanding opportunities and choice.

APPENDIX J

SCREENING and ASSESSMENT TOOLS to DIVERT PEOPLE from INSTITUTIONS

One of the most significant barriers to community integration is lack of information about what is available. To attempt to address this, Connecticut has had in place several screening processes for individuals living in institutional settings and those considering institutional placement.

1. Elder Home Care Screening

On the assumption that it is easier to divert people from institutional placement than to get them back into the community after they have lost their housing, the Connecticut Home Care Program for Elders has included a pre-screening component from its inception in 1987. Originally called the Long-Term Care Pre-admission Screening and Community Based-Services Program (PAS/CBS), the program mandated that hospitals provide information about home care prior to discharging an older person to a nursing home. It also required that nursing homes assure that any older person within the home care program's income guidelines received the program brochure and application form prior to admission. In fact, under the original program design, the only persons who were allowed admission to the home care program were those who had contacted a nursing home and been deemed likely to be admitted within two months.

Individuals who are within the program's guidelines (and therefore likely to qualify for Medicaid in the nursing home within six months) are screened to confirm that they need the level of care provided by the nursing home, and that they have been given information about home care as an alternative. These screening activities have reduced the likelihood that elders choosing nursing homes do so without information about available options in the community. However, this screening activity is limited to elders and to those whose income is within certain limits. Younger persons with disabilities and older persons with income over the program's limits are not screened, and can go into nursing homes as long as their doctor certifies that they are qualified. For those seeking Medicaid reimbursement for a nursing home stay, a review of the level of need takes place prior to payment, but not prior to the nursing home admission.

Nursing Home Screening - Pre-Admission Screening/Annual Resident Review (PAS/ARR)

In the 1970s and early 1980s, the largest number of persons under age 65 entering nursing homes nationally were persons diagnosed with mental retardation or mental illness. Following a major study of nursing homes, Congress passed the Omnibus Budget Reconciliation Act (OBRA) of 1989, which mandated a wide range of nursing home reform activities. Included within this Act was a requirement for PAS/ARR for persons with mental retardation or mental illness. Connecticut built on the existing screening process established for elders, and adapted its process to require identification of persons with mental illness and mental retardation who were applying for nursing home admission. These individuals were required to receive an assessment of their level of need and consideration of community options prior to admission to a nursing facility.

The PAS process requires that prior to admission to a nursing home, all persons diagnosed with mental retardation or mental illness be reviewed by the appropriate mental retardation or mental health agency in the State, which would then make a determination about whether nursing home placement was necessary and appropriate, and whether an alternative setting might be more appropriate. [The ARR process similarly required identification of persons with these diagnoses who were already in nursing facilities, and required that they be reviewed annually to determine whether continued stay in the nursing home was appropriate. Congress removed the mandate for the ARR activities in 1996.]

Although the PAS process does not include federal funding to provide community alternatives, the screening and review activities helps to assure that another large group of individuals receives information about community alternatives before accepting institutional placement. The Departments of Mental Retardation (DMR) and Mental Health and Addiction Services (DMHAS) has attempted to divert individuals where the State's resources allowed.

3. Other Screening Activities

As part of its plans, policies and practices, the Department of Mental Retardation has established a continuous assessment process, known as the EMPOWER process, for individuals at the Southbury Training School. At least quarterly, individuals (and/or their legal guardians) are asked whether they would like to pursue alternatives. These discussions are documented. If the individual and their

guardian choose to pursue a community placement, then the planning and resource development continues. If the individual or their guardian choose not to pursue a community placement, no further action is taken until the next quarterly review. All individuals (with their legal guardians, as applicable) who have chosen to pursue community placement are being assisted in the planning and resource development process, and placements are continuing.

Also, as part of its plans, policies and practices, the Department of Mental Retardation utilizes the annual Overall Plan of Service meeting to review the individual's (and/or their legal guardian's) interest in community placement and to discuss the full team's recommendation regarding the necessary supports or program type that would ensure the success of a future placement. In addition, as part of the Overall Plan of Service for those individuals who live in ICFs/MR, there is a Utilization Review for each individual which requires an annual "recertification for need for continued stay." Also, every six months there is documentation required to ensure that the resident continues to need an ICF-MR level of care.

In DMHAS' long-term and acute care facilities, each person works with staff from the hospital and his or her local mental health authority (LMHA) on a plan of discharge to the most appropriate lower level of care. (An LMHA develops, maintains and manages a comprehensive system of mental health treatment, support services and rehabilitative services for a designated catchment area in the State.) The need for discharge plans to include intensive community support services requires consistent and careful hospital/community collaboration. It is DMHAS' goal that people are discharged to a community of their choice with supportive services.

Under the Nursing Home Screening Program mentioned previously, nursing home applicants who may have some capacity for living in a supported community setting are identified. While the person may require nursing home level care at the time of screening, recommendations are made to the facility to provide or obtain rehabilitative services that will enable him or her to return to the community. Through a contractor, DMHAS provides for follow-up and consultation services to link the person and nursing home staff with local case management services. Nursing home applicants who are active clients of DMHAS are followed by an LMHA. DMHAS also collaborates with the Connecticut Long-Term Care Ombudsman Program in identifying nursing home residents who may want to return to the community.

On a continuous basis, under the screening program, DMHAS tracks long-term nursing home residents identified to have a serious mental illness. Again, a certain number of these residents are active DMHAS clients and are followed by an LMHA. If the person chooses to return to the community and it is possible to do so, the LMHA coordinates a planned orderly discharge. For residents not actively engaged with DMHAS, nursing homes have been advised that an LMHA may be able to provide assistance with services.

Finally, the Department of Children and Families (DCF) provides ongoing case management for children who are in out-of-home care, including those in residential placements. These case management activities are guided by an individualized service plan for every child in DCF's care, which includes identification of the level of care and intervention required to meet the child's needs. This process, along with other methods of identification and reporting, allows DCF to track and monitor the number of children in residential placements who are ready for discharge to a less restrictive, more community-based placement. The challenge is identifying and accessing the appropriate community resources necessary to meet the child's needs.

In the Olmstead decision, the Supreme Court references community services being provided as long as "the State's treatment professionals have determined that community placement is appropriate." The State must then decide who should make this determination. Clearly, in the processes described above, State staff or State-funded contractors are involved in identifying individuals who are appropriate for deinstitutionalization. Advocates have raised a question about the appropriateness of having direct providers in an institution make decisions about the appropriateness of community services. The Supreme Court did not give any further guidance on this point. However, at least in regard to services provided by Medicaid, individuals are always allowed to get second opinions, and they can certainly elect to do so in order to seek an independent professional judgment about whether community services are appropriate.

4. Future Screening and Needs Assessment

Most current screening activities are focused on diverting individuals from institutional settings rather than on deinstitutionalization. It is often much easier to supplement an existing service plan for an individual in the community, who already has a home and a circle of supportive friends, than it is to help someone start over after he or she has lost all direct ties to the community.

Individuals who are currently institutionalized also need to know they have choices, and they need to be given the chance to explore options to live in the community. Many community services may have been developed after persons were institutionalized, and if they are uninformed, they will not be in a position to ask for these alternatives. Direct outreach to all institutionalized persons would address this problem, but the extent to which this can be done is dependent upon the available resources.

To address these problems, in July 2001, the Connecticut Department of Social Services (DSS) applied for a Nursing Facility Transition Grant offered by the Health Care Financing Administration (HCFA)¹⁷ of the Department of Health and Human Services. DSS was notified in September 2001 that Connecticut was chosen to receive \$800,000 over a three-year period to:

- a. Develop an effective system for transitioning individuals in nursing facilities who are appropriate and desire to live in the community;
- b. Research and implement best practices in nursing facility transition;
- c. Design and implement an effective outreach campaign to better inform nursing facility residents and their families about long-term care alternatives; and
- d. Design professional development and value-based training for targeted audiences that includes information about needs of persons with disabilities, principles of independent living, self-determination, social role valorization, and cultural diversity.

¹⁷ HCFA is now known as the Center for Medicare and Medicaid Services (CMS).